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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Sciences
DOCTOR OF PHILOSOPHY IN NURSING

Exploring the Homeless Persons Perception of Living in a
Long-Term Care Facility

by

Janice Woods

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the
Requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

May 2019

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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Sciences
DOCTOR OF PHILOSOPHY IN NURSING

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DISSERTATION: Exploring the Homeless Persons Perception of Living in a
Long-Term Care Facility

DISSERTATION

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Abstract

Objective: The purpose of this study was to explore the lived experiences of homeless persons admitted to a nursing home facility. Originally, the study was to explore their understanding of and their experience with advance health care planning; coincidentally, the participants were more open to their experience of living in a long-term care facility.

Method: A convenience sample of 13 participants (12 male, 1 female) at four long-term care facilities in Southern California were interviewed about their perception of advanced health care planning, including the physician's orders for life sustaining treatment (POLST); a consent form required in all nursing homes. Social workers employed at these facilities helped to identify potential participants. Transcribed interviews were analyzed utilizing Colaizzi's (1978) method for phenomenological research until saturation of the themes was attained.

Results: Five themes emerge among these vulnerable homeless individuals: (a) lack of self-efficacy, (b) lack of awareness of health, (c) locus of control, (d) perception of death, and (e) yearning for a true home.

Conclusions: Most participants lacked family support, financial support, and had a history of drug abuse. All of the participants were diagnosed with at least one geriatric syndrome, were unaware of their health status, and had little-to-no communication with their health care provider. Further research is needed to explore how health care providers and policymakers can educate and inform this vulnerable population in the meaning of advance health care planning.

Key words: homeless, homelessness, advance health care planning, long-term care, nursing home, POLST.

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Dedication

I would like to dedicate my dissertation to my daughter, Zoe Woods, who was born during my PhD program. Mommy loves you so much and I want you to know that you can achieve your dreams when you work hard for them. Mommy is done with school now and we are going to have years of love and fun.

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Chapter 1

Introduction

The purpose of this research study was to understand the lived experience of homeless persons admitted to a long-term care facility and their experience with advanced health care planning. The researcher sought to study this population, their perception of advance health care planning, and examine barriers to this planning process. Furthermore, the investigator explored formerly homeless persons' perception of their health, the use of advance directives, and their awareness of physician's orders for life sustaining treatment.

Issues to Consider with Homelessness

One of the most vulnerable populations in America is homeless individuals (Kimbler, DeWees, & Harris, 2017). Homeless people are often stigmatized and stereotyped as difficult, hard to please, and demanding (Hudson, Flemming, Shulman, & Candy, 2016). These homeless individuals frequently utilize hospitals for all of their health care needs, including primary care and preventive services (Brown & Steinman, 2013; Page, Thurston, & Mahoney, 2012). Additionally, end-of-life medical expenses tend to be the costliest. As reported in Dobbin's (2016) study, 2014 Medicare payments were estimated at \$597 billion for end-of-life care services. The complex issues contributing to homelessness are vast including the decline in affordable housing; lack of affordable medical insurance; and increased longevity with chronic, disabling conditions. Nevertheless, there is limited research about advance health care planning for formerly homeless individuals who have been admitted to nursing home (Ko, Kwak, & Nelson-Becker, 2015).

Homelessness is defined as a person having an unstable and temporary place to sleep at night (Cagle, 2009; Tarzian, Neal, & O'Neill, 2005). Living arrangements range from staying at a friend's home to sleeping in a shelter, vehicle, or on the street (Brown et al., 2017; Lee et al., 2016). Homelessness can affect all ages, but chronic homelessness is more commonly seen in older adults (Henwood, Byrne, & Scriber, 2015) due to the lack of job opportunities or disabling medical conditions (Sumalinog, Harrington, Dosani, & Hwang, 2016). Homeless people are hampered in accessing health care due to insufficiencies in housing, employment, family support, and transportation, and may also be compounded by mental illness (Kushel, 2016). Limited contact and mistrust of society are some attributes that make this one of the most difficult populations to research (Vance, 1995).

Housing. According to the Los Angeles Homeless Service Authority (2018), an estimated 52,765 homeless individuals were living in Los Angeles County in 2018. Nationwide, California accounted for 26% of the homeless population (Henry, Watt, Rosenthal, & Shiviji, 2016); the highest homeless concentration in the United States. According to Goldberg, Lang, and Barrington (2016), the increase in the number of homeless individuals over the last 20 years can be attributed to decreased affordable housing, lack of employment, reduced government assistance programs, limited access to health care, and sparse access to mental health.

Affordable-housing issues affect approximately 38% of older adults; 21% are categorized as having a severe cost burden (Goldberg et al., 2016). One common misconception is that older adults own their homes outright; in reality, most either rent or still have mortgage payments (Goldberg et al., 2016). Social Security retirement benefits

alone are inadequate to cover the expenses for basic housing and food (Goldberg et al., 2016).

Most homeless older adults do not qualify for Social Security retirement because of their time worked (Sorrell, 2016). Many rely on supplemental security income (SSI) that pays, on average, \$733 per month (Sorrell, 2016). To qualify for SSI, the beneficiary must be younger than 65 and be completely disabled (MacGregor, 2014). In some states such as California, this level of payment is barely sufficient for room and board alone. Qualifying for SSI is difficult and based on diagnosis, disability type, duration, and severity of functional impairment (MacGregor, 2014). In the chronic homeless population, many do not get approved (Burt, Wilkins, & Locke, 2014).

Health. For people aged 65 and older, the average annual cost for out-of-pocket health care expenses is \$4,734 per year in excess of the cost of their Medicare insurance plan (Goldberg et. al., 2016). In an effort to afford health care and housing, older sick adults must continue to work (Brown, Thomas, Cutler, & Hinderline, 2013). Previous studies reported significant correlations on housing status and personal health (Salem & Ma-Pham, 2015; Waldbrook, 2013). Most homeless people die from chronic disease rather than accidents, homicide, or lack of shelter (Page et al., 2012).

Most homeless adults in their 50s have at least one chronic disease (Brown et al., 2017; Salem & Ma-Pham, 2015). Common chronic conditions seen in the homeless population include hypertension, diabetes, and hyperlipidemia (Grenier, Sussman, Barken, Bourgeois-Guerin, & Rothwell, 2016); however, their conditions worsen because they lack access to medications, free or low cost medical care, nutritious meals, and a healthy environment (National Health Care for the Homeless Council, 2016a). For example, diabetic wounds will worsen if blood sugars are not well managed. If a

homeless person living in an unsanitary environment has no one to assist with wound care, infections or even amputation may ensue. Pre-mature aging has been associated with homelessness (Salem & Ma-Pham, 2015). Chronic conditions are also exacerbated by limited resources and extensive wait times (Salem & Ma-Pham, 2015).

Brown et al. (2017) reported that homeless people may display multiple symptoms associated with impaired functions seen in geriatric populations, including reductions in cognition, hearing, and vision, as well as issues with mobility, falls, depression, fragility, and depression. These symptoms have been termed *geriatric syndromes* and are known to be preventable and manageable (Brown, Kiely, Bharel, & Mitchell, 2012; Henwood, Katz, & Gilmer, 2015). Still, homeless people experience more geriatric syndromes and have a higher occurrence of being institutionalized (Brown et al., 2017; Brown et al., 2012). Unfortunately, as these geriatric syndromes worsen, homeless people are admitted to long-term care facilities sooner (Brown et al., 2013; Jaffe, 2017).

Cost/finance. The development of geriatric syndromes and the subsequent dependence on others needed by the homeless person result in higher health care costs with the nursing home admission. According to the Henry J. Kaiser Family Foundation (2017), the average cost of nursing home care averages \$82,000 per year; triple the average annual senior income. Many nursing homes choose not to admit homeless individuals due to their younger age, behavioral issues, and lifestyle choices (Jaffe, 2017). They also prefer limited stays for these residents as the reimbursement rate is much lower when compared to short-term Medicare payers. Jaffe (2017) also noted that inappropriate long-term resident discharges from nursing homes freed up limited beds for higher paying, short-term stays (Jaffe, 2017).

Health care insurance. Medi-Cal is the California state insurance program for Medicaid (Burt et al., 2014). In 2013, Medi-Cal coverage expanded from low income families, children, seniors, blind, and disabled people to a defined limit of income: below 133% of the federal poverty level (Burt et al., 2014). Approximately 63% of nursing home patients had Medicaid payers, but and only 6% of Medicare beneficiaries used this insurance (Harbage Consulting, Haycock, Pagel, & Jennifer, 2017). With the Affordable Care Act, approximately 11 million people classified as the working poor were able to access health care coverage through the expanded Medicaid program (Harbage Consulting et al., 2017). In order to meet eligibility requirements, Medicaid recipients must re-enroll every 6 months (Burt et al., 2014). As homeless individuals have limited access to phones and are unable to provide a permanent address, these requirements put them at high risk of losing their health care benefits (Harbage Consulting et al., 2017).

Historically poor reimbursement rates limit the number of providers, typically community clinics, who are willing to deliver health care under Medi-Cal (Kaiser Health News, 2015). Even fewer specialty practices accept Medi-Cal insurance. As a result, Medi-Cal patients may need to travel extensive distances and wait longer for an appointment to see a willing specialist when compared to patients with other forms of health insurance (Kaiser Health News, 2015). Nationally, Medicare and Medicaid are moving toward performance-based payment models utilizing managed care, coordinated care, and accountable care organizations that are willing to share costs if the results decrease the number of emergency visits and hospitalizations (Holtrop, Luo, & Alexanders, 2015). Strategies include intensive case management through phone or in-person contacts to help patients navigate the health care system (National Health Care for the Homeless Council, 2016b).

Advanced health care planning. Since the Patient Self-Determination Act of 1996, patients must be informed about and consent to their treatment (Brown, 2003; Miller, 2017). With numerous co-morbidities, many homeless patients suffer from chronic, incurable conditions but they are nonetheless manageable (Waldbrook, 2015). Some of these patients would benefit from palliative care for their symptoms (Podymow, Turnball, & Coyle, 2006); however, the literature did not reveal any research on formerly-homeless nursing-home residents and their perception of palliative care or end-of-life options. According to Huynh, Henry, and Dosani (2015), one reason for the lack of advance health care planning could be the lack of social support. Another barrier could also be the homeless person's fear of becoming more dependent as the end of life draws near (Ko et al., 2015).

An advance directive is a legal document identifying a health care agent in the event of one's incapacity (Brown, 2003; Lum & Sudore, 2016; Watson, 2010). Once a patient reaches the age of 18 years, medical professionals may advise them to execute an advance directive (Lum & Sudore, 2016; Watson, 2010). Two witnesses must sign an attestation to the patient's treatment wishes, such as the wish to prolong life (Watson, 2010). Though the advanced directive is completed in the presence of medical personnel, it can be difficult to interpret end-of-life care wishes and has been found to be ineffective in the hospital setting (Jesus et al., 2014; Lum & Sudore, 2016; Miller, 2017). In an effort to promote advance directives, Medicare now provides payment to providers if advance health care planning is discussed during the patient appointment (Dobbins, 2016). As for the homeless population, completing an advance directive may be difficult as the standard form requires at least a 12th grade reading level (Sudore et al., 2007).

In 1991, a form entitled, physician's orders for life sustaining treatment (POLST), was developed at the Center for Ethics in Health Care at Oregon Health Sciences University (Kim, Ersek, Bradway, & Hickman, 2015). This portable, legal document allows patients to decide the forms of medical treatment they receive in the event of an emergency and range from aggressive treatment to comfort measures (Hickman, Nelson, Smith-Howell, & Hammes, 2014; Tolle & Tilden, 2002). Forty-seven states have adopted various versions of the POLST form (California Health Care Foundation 2013). The POLST form describes three categories for treatment: cardiopulmonary resuscitations with full treatment; do not resuscitate with full treatment or selective; and comfort measures (Schmidt, Zive, Fromme, Cook, & Tolle, 2014). Cardiopulmonary resuscitation attempts to reverse the illness and return the patient to homeostasis (Schmidt et al., 2014). Do- not-resuscitate is providing conservative treatment, such as non-invasive ventilation or intravenous fluid hydration (Schmidt et al., 2014). Effective in 2016, California passed AB 637 allowing nurse practitioners and physicians assistants to sign the POLST order form (Coalition for Compassionate Care of California, 2015). Additionally, in nursing homes and other long-term care facilities, it is a requirement that residents have a signed POLST form in every chart (Rahman, Bressette, Gassoumis, & Enguidanos, 2016).

Significance

No research could be identified addressing homeless individuals who were admitted to long-term care facilities and their perception of advance health care planning. As this is a vulnerable population that is no longer able to live in the community, these individuals have unfortunately become institutionalized. This qualitative study seeks to form a foundation of knowledge that will promote interventions to enhance the quality of advance health care planning in this population.

Purpose

The purpose of this research study is to describe the perception of POLST in a group of homeless persons currently residing in a long-term care setting, to identify their perception of a meaningful death, and to explore their awareness of advance health care planning.

Research Question

What is the perceived meaning of advanced health care planning among homeless persons admitted to a long-term care facility?

Brief Overview of Research Design

A phenomenological, qualitative research design will be used to explore the lived experiences of formerly homeless, nursing-home residents and their experiences with advance health care planning. Phenomenology is an appropriate method for this study as no research could be identified on the lived experiences of homeless people being institutionalized and their perception of advance health care planning. A purposive sample of nursing home residents residing in Los Angeles county was obtained. Data were collected through recorded face-to face interviews. All interviews were transcribed and coded for themes.

Assumptions

The assumptions guiding this phenomenological study included:

1. Homeless people are a vulnerable population through their lack of resources and unstable living environment
2. Homeless people are stigmatized and ostracized in health care settings
3. No research has been published about homeless people living in long-term care facilities and their perception of advance health care planning.

Chapter 2

Literature Review

The purpose of this chapter is to review previous research on homeless populations and the use of advance health care planning. Due to the limited number of published studies on advance health care planning of homeless people living in long-term care, this chapter will review research on homelessness, health, case workers' perception of homeless people, and progress in research on advance health care planning. The philosophical underpinnings will apprise this phenomenological study and will aid in supporting this approach.

Homelessness and Health Issues

Environment and health directly affect one's current health condition (Grenier et al., 2016; Page et al., 2012). Several studies described homeless people's perception of their own health as poor, particularly in older adults (Henwood, Byrne et al., 2015; Kimbler et al., 2015; Taylor, Kendzor, Reitzel, & Businelle, 2016). Research has reported that the homeless individuals tend to die at a younger age and suggested that formerly homeless older adults die sooner than the general population (Henwood, Byrne, et al., 2015; Kimbler et al., 2015). In one cross-sectional study, Kimbler et al. (2015) analyzed characteristics of a homeless population in emergency shelters. Utilizing orally-administered surveys of 750 homeless participants, this study revealed that older adults were more likely to stay in medical hospitals prior living in homeless shelters and less likely to receive mental health treatments. Older adults who were homeless for extended periods of time were more likely not to have an emergency contact. The length of time in homelessness for older adults positively correlated with the length of time spent residing on the streets. In a similar study of formerly homeless individuals, Henwood et al. (2015)

reported that the average death in this population occurred between 45 and 64 years of age; 72% died of natural causes, compared to 49% of the general population; and 21% died of cancer, versus 7% of the general population. The results of the study revealed that formerly homeless people were in poorer health than the general population; however, formerly homeless individuals were healthier than their actively homeless counterparts.

While other countries, including Canada, also grapple with homelessness under their respective universal health care programs, there is a misconception that increased access to health care alone would provide improved outcomes. In their retrospective study on deaths in Alberta, Canada, Page et al. (2012) examined the records of 132 homeless people. As with studies in the United States, these authors reported that the average age of death was 46 years, generally men, and the most frequency reason for death was related to drug and/or alcohol abuse (Page et al., 2012).

Brown et al. (2017) argued that environment and health were significantly correlated. In a sample of 350 homeless people 50 years of age and older, Brown et al. focused on geriatric conditions of these Oakland, CA residents. Although their living environment differed (e.g., unsheltered, cohabitated, institutional), geriatric syndromes were prevalent in all when compared with the general population of adults over the age of 50 years (Table 1).

Table 1

Impairment in Homeless Population Compared with the General Older Population

	Homeless Population (Median = 58 Years)	General Population > 50 Yrs. (Median = 80 Years)
Impaired - Activities of daily living	38.9%	22.6%
Impaired - Instrumental activities of daily living	49.4%	40.4%
Cognitive impairments	25.8%	12.0%
Visual impairments	45.1%	13.8%
Urinary incontinence	48.0%	41.1%

Adapted from “Geriatric conditions in a population-based sample of older homeless adults,” by R. T. Brown et al. (2016), *Gerontologist*, 57, p. 763. Copyright 2016 by the Gerontological Society of America.

Choosing a different approach, Lee et al. (2016) analyzed data by examining types of homelessness and social support. The participants who were cohabiters or *couch surfers* were primarily women, who were able to avoid homeless shelters. They also had the highest social support with family. Lee et al. also found higher occurrences of chronic illness and cognitive impairments, but lower usage of illicit drugs in the older adults.

Both Salem and Ma-Pham (2015) and Waldbrook (2015) performed qualitative studies to formulate explanations of health deterioration among the homeless population. Participants in both studies discussed how chronic conditions were exacerbated by homelessness. The most common theme was the environment (e.g., harsh weather conditions) that increased susceptibility to pneumonia. Secondly, the lack of nutrition with corresponding increased weight loss and vitamin deficiencies contributed to poorer health. Both studies discussed the inability to select healthy food options. The third factor was the lack of access to health care; many who lived on the streets had been robbed

and/or lost their insurance cards. Their source of immediate care was the emergency department due to limited primary care appointments and long wait times. Drug addiction and pain management were other barriers to staying sober and their connection to mental health clinics was limited, leading to ineffective detoxing and perpetual drug abuse as a proxy for appropriate treatment. All of these common themes helped to explain reasons for the multiple health issues seen in homeless individuals.

Horn (2008) discussed two cases of homeless older adults finding placement. Both participants described how they were could not afford housing and their subsequent health-decline. The participants gradually deteriorated to the point where they were not able to perform their daily activities and eventually met the criteria to be admitted to a nursing home. Nonetheless, living in nursing homes is not a cost-effective substitute for homelessness and should only be a last option for housing homeless individuals.

Case Workers

Few studies identified how case workers could help homelessness. MacGregor's (2014) study included interviews with 14 case workers. These case workers assisted homeless individuals in applying for Social Security's Supplemental Security Income (SSI) program. All of the case workers reported extreme difficulty in assisting people living in shelters. Identifying available housing was reportedly easier for women and children as compared to homeless older adults. Each case worker described the arduous task of identifying a medical diagnosis that met the criteria for SSI disability. In addition, case workers reported difficulty in locating a medical provider who would diagnose a patient as disabled under SSI criteria. Completing applications proved difficult for people who were less educated, instead relying on case worker to assist them with the paperwork. Dennis, McCallion, and Ferretti (2012) used the self-determination theory in

their interviews of five professionals working with the homeless population. The three major themes that emerged from their analysis were client-worker services relationships, obstacles, and self-determination that led to the desired outcome of housing. The process of relationships was sometimes difficult because clients lacked follow-through or were non-compliant. Homeless clients with a criminal history were hard to place. These professionals had to serve as guides for their homeless clients. Having permanent housing could motivate these clients, fulfilling their need for a sense of belonging (Dennis et al., 2012). Both of these studies explained the important role of case workers in a homeless person's placement.

Palliative Care and Homelessness

Palliative care for the homeless population is a relatively new concept in the United States; however, Canadian shelter-based palliative care has become more common. A study by Podymow et al. (2006) provided evidence that palliative care with hospice could save \$1.39 million dollars in health care costs for 28 homeless individuals by receiving palliative care at a shelter. The shelter was able to provide a full-time nurse, part time licensed vocational nurse, and a 24-hour caregiver that would help with care coordination and case management. They were also able to provide a full-time physician to supervise care. The study also reported on a harm-reduction program by providing clean needles, a strict narcotic policy, and 14 grams of alcohol per day for their alcoholic, end-stage liver patients. All of the patients died under hospice care, had improved medical care, and were able to limit the use of hospital emergency rooms for symptom management only. Two U.S. studies by McNeil and Guirguis-Younger (2012) and McNeil, Guirguis-Younger, Dilley et al. (2012) also discussed harm-reduction services in providing end-of-life care and support in homeless populations.

Tarzian et al. (2005) and Ko et al. (2015) performed their qualitative studies on the homeless community's perception of end of life. In both studies, homeless participants expressed common themes: appreciating individual values, relationships, and not suffering. Both studies discussed the homeless person's spiritual connection with God in their end-of-life choices; a way to help comfort them about death. Tarzian et al. focused on relationships between the homeless person and his or her health care provider; however, the participants expressed that health care providers were not compassionate or respectful in their end-of-life discussion. Utilizing grounded theory, Ko et al. examined the homeless person's perspective of a good or bad death. Ko et al. recommended that health care providers treat homeless persons as unique individuals.

A preponderance of studies focused on providers' interactions in the care they delivered to homeless people. In a descriptive study, Hutt et al. (2016) interviewed Veterans Affairs employees working directly with the homeless population. These researchers disseminated e-mails to participants (response rate = 33%). A majority of participants reported that helping homeless veterans in finding placements was their biggest challenge. Their next most difficult challenge was care coordination. In their qualitative study, Krakowsky, Gofine, Brown, Danziger, and Knowles (2013) studied Canadian providers and uncovered that providers were not searching for placements and not giving care where the homeless were placed. The provision of care was dependent upon the homeless individual's current living arrangement: on the streets, in the hospital, or in a shelter.

Advance Health Care Directive

Limited research could be found on advance health care planning among the homeless population. Two studies with similar methods were able to demonstrate an

almost 50% increase in advance health care directives for this community. In a prospective, single-blind, randomized trial, Song et al. (2008; 2010) studied whether homeless participants completed more advance health care directives utilizing counselor guidance. With a sample of 262 people living in Minneapolis homeless shelters, data compared a control group with no personal guidance and only written instructions with an intervention group receiving guidance from a counselor. The intervention group had 37% more advance directives completed when compared to the control group. In a similar study conducted in Ontario, Canada, Leung, Nayyar, Sachdeva, Song, and Hwang (2015) examined a cohort of 205 homeless people living in shelters. This study also involved a counselor-guided intervention, but no control group or randomization. Likewise, advance health care directive completion increased by more than 50%. Furthermore, they found no correlation between the participants' socio-demographic characteristics and the completion of the advance directive. More than one-half of the participants were able to name a surrogate decision-maker; however, 94.1% of the participants wanted full resuscitation if they were able to return to their previous function. The Lueng et al. and Song et al. studies demonstrated that counselling with one-to-one education for advance health care directive completion was effective among homeless participants. These studies recommended that providers should be more open to educating patients about the advance health care directive.

Nedjat-Haiem et. al (2017) conducted a qualitative study on initiating end of life discussions and the providers who begin that process. In interviews at two major medical centers in central Los Angeles, they were able to engage 79 medical and non-medical providers. The common theme in their qualitative study was that physicians were taking part in end of life discussions earlier, especially regarding prognosis. Shared

responsibility for end of life discussion was also noted amongst nurses, social workers, and chaplains.

Physicians Orders for Life-Sustaining Treatment (POLST)

Schmidt et al. (2014) studied the POLST Registry of Oregon, established in 2009. This registry was created to assist emergency personnel on medical decisions according to POLST forms signed by the patient. Schmidt et al. reviewed 31,294 of the POLST forms entered into the registry. The average age of the patient was 76, with one-third of registrants opting for DNR comfort, DNR selective, and full treatment. They found that women in nursing homes were more likely to complete POLST. Most men had care takers and completed the POLST form closer to death.

Quality of Decision-Making

One of the pioneers in Oregon's original POLST form is Susan Hickman, PhD. She and her team now focus on the quality of POLST decisions. Hickman, Nelson et al. (2014) researched 151 nursing home residents, primarily Caucasian persons who were initially discharged from Gundersen Lutheran Medical Center, WI. In their descriptive study, these researchers performed chart extractions and examined a convenience sampling of residents or their surrogates to participate in interviews about the POLST form. They uncovered that there was no code status change amongst the residents from the hospital to the nursing home. Nevertheless, during the interviews of the residents, a common theme was that neither the prognosis nor the goals of care were clearly explained in the hospital. Continuing their exploration of the quality of decision making further, Hickman, Hammes, Torke, Sudore, & Sachs (2017) conducted a pilot study of two nursing homes in the same area. In a relatively small sample of 28 nursing home residents or their surrogates, they interviewed participants: 7% of those agreeing to CPR

were confused by the definition of CPR, 18% were confused about the level of medical intervention, and 21% did not understand the role of antibiotics. They found a lack of standardization in end of life discussions and the explanation of the POLST form.

Two research studies suggested that patients' decisions were based on how providers explained their prognosis and the provider's own perception of the patient's end of life wishes. In a secondary data analysis of 196 male veterans, Downey, Au, Curtis, and Engelberg (2013) reported that clinicians overestimated patients less-aggressive treatments. In another secondary analysis (i.e., Coping with Cancer II data), Epstein, Prigerson, O'Reilly, and Maciejewski (2016) stated that, out of 178 advance cancer patients, only 5 % actually understood their disease and prognosis. Both studies revealed additional, unwanted, aggressive treatment due to the lack of communication with health care providers. In a cross-sectional review, Clemency, Cordes, Lindstrom, Basior, and Waldrop (2017) examined 100 Medical Orders for Life-Sustaining Treatment (MOLST), similar to the POLST, in one New York hospital emergency department. In this study, physicians were asked to collect the MOLST upon completion. Data extracted from the MOLST forms revealed that 69% of the forms were incomplete. There were no differences in decisions between the patients and their proxies; however, the discussion about goals of care were unclear.

POLST in the Nursing Home

Two studies examined POLST forms in California nursing homes. Jennings et al. (2016) extracted data on 296,276 residents from the California Minimum Data Set S and Rahman et al. (2017) audited POLST forms in 13 Los Angeles, CA nursing homes. Both studies revealed that 10% to 15% of residents did not have a POLST form in their chart. Jennings et al. focused on the number of nursing home residents who completed the

POLST. Long-term nursing home residents were more likely to have a completed POLST when compared to short-term residents. Jennings et al. reported a large number POLST forms were incomplete due to the lack of signatures, either from the proxy, patient, and/or physician. Rahman et al. assessed completeness of the POLST form, the wishes of the resident according to the POLST, and whether the physician's orders were consistent with the POLST. Both studies agreed that they could not evaluate the quality of the end-of-life discussion based on the POLST.

In a case study of 60 non-randomized, care plan meetings in a long-term care setting, Hartle, Thimons, and Angelelli (2014) had a nurse practitioner participate in the POLST discussion. Nursing home residents in this study averaged 4.5 on the Charlson Comorbidity Index Score; a moderately high mortality rate with an increase need for hospital resources. This study reported that, with nurse practitioner involvement, 23% of POLST forms had a change the code status.

Conclusion

Since the Great Recession, there has been a surge of homelessness among older adults in Los Angeles County (Los Angeles Homeless Services Authority, 2018). Studies have described how environment, relationships, health, mental illness, and finances contribute to homelessness (Salem & Ma-Pham, 2015; Waldbrook, 2015). Homeless individuals are aging faster, dying sooner, or are institutionalized at a rate higher than people with stable housing (Brown et al., 2012). Research has also revealed that homeless people experience barriers to health care, especially for manageable diseases (Brown et al., 2012; 2017). Research examined palliative and hospice care in homeless shelters and concluded that too few interventions have been implemented (McNeil et al., 2012). Advance directives and POLSTs, effective tools to discuss end-of-life wishes for

homeless individuals with serious illnesses, are often lacking or incomplete (Leung, Nayyar et al., 2015; Song et al., 2010). Research described weaknesses in providers' explanations for advance health care planning and poor understanding from their patients regarding their disease states (Epstein et al., 2016; Hickman et al., 2014). This dissertation study endeavored to explore advance health care planning in homeless nursing home residents as well as residents' understanding of the need to plan for the end of life.

Philosophical Underpinnings

A paucity of research could be found on advance health care planning among homeless people admitted to long-term care. A phenomenological approach for this study explored homeless resident's perception of advance health care planning.

Phenomenology is a method employed to extract knowledge of the unknown. This qualitative method helps to identify social processes, barriers, and influences of advance health care planning among homeless persons in long-term care (Starks & Trinidad, 2007). The intent of descriptive phenomenology is to have meaning in a person's experience of the world, space, and time (Priest, 2002). Based on Heidegger's existential philosophy, *dasein* is the lived experience; phenomenology explores the world as seen through the lens of the person experiencing it (Holloway & Wheeler, 2010) and is constantly self-interpreting experiences without knowledge (Wertz, 2005). Though the science of phenomenology, one may excerpt human language into common themes that go beyond a sole event (Holloway & Wheeler, 2010). The goal of this study was to generate new knowledge, ascribe meaning, provide a comprehensive view of homeless people living in long-term care facilities, and share their experience with advance health care planning.

Chapter 3

Methodology

This chapter introduces phenomenology as the fitted research method for this study. Included in this discussion is historical phenomenology, methods, data management, and analysis.

Phenomenology as a Research Method

This descriptive qualitative study pursued the lived experience of homeless people admitted to long-term care facilities and their experience with their providers for advance health care planning. Using phenomenology in nursing research is pertinent to establish a knowledge base where little is known (Flood, 2010; Jasper, 1994). This study describes the care that patients received and offers insight to the future of care for this patient population (Converse, 2012). Phenomenology focuses on the lived experience of a person in time, space, body, and lived human relationships; the investigator reviews the person's story to interpret meaning in the person's experience (Priest, 2002; Starks & Trinidad, 2007). Qualitative studies are beneficial for future quantitative research as they help to generate new variables for further understanding (Polit & Beck, 2012).

To understand phenomenology, one must look closer at the history and development of this qualitative research method. Phenomenology developed over time in three phases: preparatory phase, German phase, and French phase (Lictman, 2014). The preparatory phase consisted of Franz Brentano (1838-1917) and Wilhelm Dilthey (1833-1911), philosophers that started the ideology of phenomenology (Holloway & Wheeler, 2010). During the German phase, the most influential philosophers included Edmund Husserl (1859-1938), focusing on descriptive phenomenology, and Martin Heidegger (1889-1976), known for his substantial contributions to hermeneutics (Flood, 2010). The

French phase consisted of Gabriel Marcel (1889-1972), Jean-Paul Sartre (1905-1980), and Maurice Merleau-Ponty (1908-1961), who focused on existentialist phenomenology (Lictman, 2014).

Phenomenology's earnest beginning is ascribed to Franz Brentano, a German philosopher who created the basic concept of intentionality (Lictman, 2014).

Intentionality is about physical phenomena and mental phenomena connected to the intended object (Priest, 2002). Brentano began by describing human characteristics and their association to objects (Dinkel, 2005; Lictman, 2014).

His student, Edmund Husserl, often considered *the father of phenomenology*, took the concept of intentionality to develop the notion of consciousness (Converse, 2012; Ordille, 2016). Husserl postulated that knowledge came from experience (Converse, 2012; Dinkel, 2005) and believed that all humans are conscious about their surroundings or objects (Holloway & Wheeler, 2010). He was able to build a systematic approach to phenomenology through reduction (Converse, 2012; Holloway & Wheeler, 2010) and recognized that a person might possess his or her own biases, but through reasoning, one could set one's own biases aside; a term Husserl called epochs (Wertz, 2005). Husserl identified the first epoch as bracketing to deliberately stop all assumptions; to identify the subject prior to the research knowledge (Starks & Trinidad, 2007; Wertz, 2005). Husserl considered this to be a *natural attitude* (Wertz, 2005). The investigator must view the subject without meaning before identifying the problem (Wertz, 2015) in order to view phenomena prior to scientific acknowledgement (Lictman, 2014). Husserl's second epoch was methodological absences; recognizing the researcher's own biases and feelings of the subject, then putting them aside (Wertz, 2005). Husserl argued that one

could perceive many types of meaning and his phenomenological approach was descriptive (Priest, 2002).

As a student of Husserl, Martin Heidegger envisioned Husserl's teachings at the next level (Lictman, 2014). Heidegger disagreed with Husserl about bracketing (Wertz, 2005) and concluded that phenomenology was best understood through one's environment, also known as *dasein* or one's existence in the world, in space, and in time (Flood, 2010; Priest, 2002). He believed that phenomenology was a circular notion, a *hermeneutic circle*, that looked at an individual and the world as a whole (Ho, Chiang, & Leung, 2017) and that language was the vehicle for describing one's existence (Wertz, 2015). With this understanding, the investigator could question meaning during an interview dialogue (Ho et al., 2017). Heidegger viewed the phenomenological approach as portraying and understanding human experiences (Jasper, 1994).

French philosopher Maurice Merleau-Ponty took phenomenology to the next level; from the view of an existentialist (Lictman, 2014). Valle and King (1978) described existentialism "as a formal philosophical school, seeks to understand the human condition as it manifest itself in our concrete lived situation" (p. 6). They viewed the person and his or her world as co-dependent, in constant dialogue, or as a complementary association (Valle & King, 1978). The body and mind were indissoluble and integrated with space and time (Valle & King, 1978). The key to existentialism was that the person was always conscious of the world and vice versa; there was no action or causality towards the world, just being present in the world (Valle & King, 1978). Merleau-Ponty addressed essence and situation in different forms, but the essential meanings would always be the same (Valle & King, 1978).

The phenomenological method utilized by this study was based on Duquesne University's philosopher, Paul Colaizzi (1978); that the lived experience could be used as a tool. Colaizzi argued that operational definitions must be eliminated; true to Husserl, Colaizzi bracketed prior scientific knowledge. With this methodology, the investigator must ask questions that he or she might ask of oneself; the reason for the research and one's own personal biases. The analytical procedural steps of Colaizzi (1978) included: (a) transcribe the whole participants' descriptions or *protocols* to understand their feeling; (b) statements deemed significant are extracted to review each expression and description that pertains to the phenomena; (c) meanings are formulated, deriving *meaning* versus *saying*; (d) themes are clustered according to their meaning so as to group common themes; (e) the themes are developed using comprehensive, in-depth descriptions; (f) the extensive descriptions are then condensed into central structures; and (g) these fundamental, central structures are reviewed with all participants to verify, add to, or correct the protocol.

Method of Inquiry: Applied

As homeless people admitted to nursing homes are understudied, the best scientific approach for this study is phenomenology. To promote future enquiry, this researcher endeavors to find a foundation for advance health care planning for homeless individuals in the long-term care setting. By extracting the lived experiences of this population, as well as his or her perception of advance health care planning, will generate insight into this vulnerable population and the medical decisions included in the physician's orders for life sustain treatment and advance health care planning. The specific aim of this study is:

- To explore the lived experiences of homeless persons admitted to a nursing home facility, their understanding of, and their experience with advance health care planning.

Setting and sample. Several nursing home facilities in Los Angeles County and Riverside County were approached for this study. The researcher presented study information to administrators. With the consent and permission of administrator, the researcher interviewed residents. The sample comprised homeless persons presently residing in long-term care facilities. Homelessness was defined as a person who had no permanent residence; a person that did not rent or own a home.

Inclusion criteria. (a) English speaking, (b) capacity to make his or her own health care decision according to the patient's history of physical done by their primary care provider(s), (c) presenting residing in a nursing home setting, and (d) 18 years of age or older.

Exclusion criteria. Incapacitated or cognitively impaired according to their history and physical record.

Data collection. To identify homeless residents, the researcher spoke with each facility's social services department about referring potential research subjects. During the study, activities flyers were also presented with contact information for those who wished to participate in the study. The sampling was done purposively and through the snowball effect. Frequently, homeless people would decline to be interviewed due to the distrust for health professionals and strangers; therefore, the researcher needed assistance with referrals from the facility's social workers and from other participants. The investigator asked the patient about demographic information, diagnoses, diseases, and activities of daily living. Field notes were recorded of the interview, including the

surroundings, place of the interview, and how the participant was perceived by the researcher. Interviews lasted approximately 60-90-minute and were digitally recorded. The researcher asked participants, “What is your perception of advance health care planning?” and “Have you seen this pink form?” The researcher also asked probing questions to facilitate clarification. Participants responses were extracted to the point of saturation.

Ethical considerations. Oversight of the study was provided by the Institutional Review Board (IRB) of the University of San Diego (Appendix A). The researcher presented an informed consent form to individuals meeting the inclusion criteria of the study (Appendix B). The researcher explained that the interviews were being recorded and transcribed with non-identifying information. The researcher ensured privacy and was prepared to provide mental health assistance if the subject became emotionally distressed when interviewed. The investigator also explained that the participant could drop out of the study at any time and would still be eligible for the nominal, monetary compensation; there were no consequences for not completing the study. The momentary compensation consisted of a \$25 Visa gift card for participating in the study.

Chapter 4

Data Results

Findings of Inquiry

This chapter will discuss the results of the interviews. In addition, there will be a description of the participants. Themes have been extracted from the interview transcripts. Five themes emerged from the data: (a) lack of self-efficacy, (b) lack of health awareness, (c) yearning for a home, (d) locus of control, and (e) perception of a good or bad death.

Recruitment of Volunteers

Flyers for participation in this research project were posted in activity rooms of nursing homes (Appendix C). The researcher relied heavily on facilities' social workers to introduce and refer participants. All participants were volunteers and a monetary compensation was provided for their cooperation.

Participants

A total of 13 individuals participated in this home from four nursing homes in Southern California; all geographically located in low-income communities. The average Medicare star ratings were less than 3 on a 5-point scale. The average age of participants was 54 years with a range in ages from 33 years to 72 years of age. No participant had a safe discharge plan or was awaiting placement. The participants were comprised of 12 males and 1 female. All of the participants identified themselves as Christians. With the exception of one participant, all of the individuals reported some kind of drug abuse. Most of the participants had been hospitalized immediately prior to nursing home admission and were not aware how the extent of their illness until they were placed in the nursing home. All participants had at least one geriatric syndrome. Most considered

themselves in *fair* condition and did not feel that they were appropriately placed. Other demographic information is presented in Table 2 and Figure 1.

Table 2

Participants' Demographic Information

Participant	Age (years)	Race	Gender	Geriatric Syndrome	Social Support	POLST
1	57	African American	Male	Impaired mobility	Yes - sister	FULL
2	58	Hispanic	Male	Impaired mobility	Yes - sister	DNR
3	53	Caucasian	Male	Impaired mobility	None	FULL
4	51	Caucasian	Male	Impaired mobility	Yes -friends	FULL
5	72	Caucasian	Male	Impaired mobility	Yes -sister/ pet rabbit	FULL
6	68	Caucasian	Male	Impaired mobility	Yes - father	FULL
7	48	Caucasian	Male	Memory loss	None	FULL
8	51	Caucasian	Male	Chronic pain	Yes - son	FULL
9	64	African American	Male	Impaired mobility- dizziness	None	FULL
10	53	Hispanic	Male	Impaired mobility	Yes - daughter	FULL
11	33	Hispanic	Male	Psychiatric disorder	None	FULL
12	68	Hispanic	Male	Impaired mobility	Yes - daughter	FULL
13	38	Hispanic	Female	Impaired mobility	None	FULL

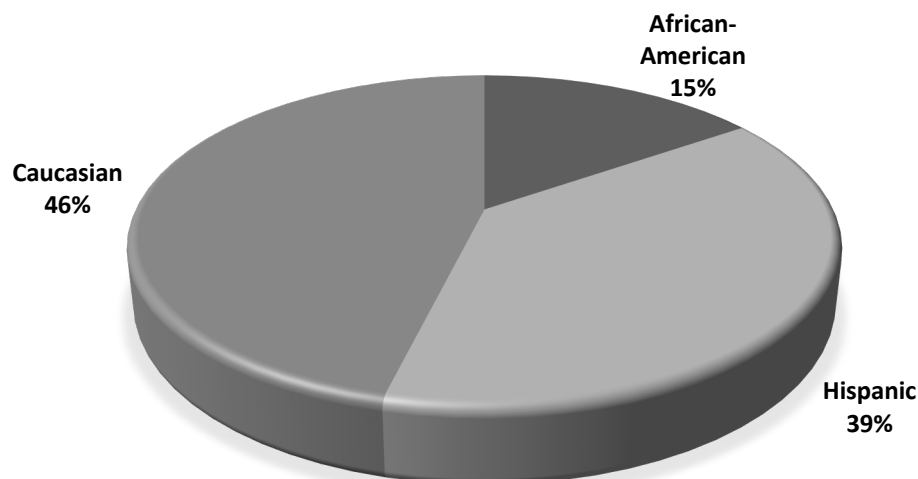


Figure 1. Race and ethnicity of study participants.

Lack of Self-efficacy

Self-efficacy is a belief that one can accomplish a task based upon one's own abilities (Eller, Lev, Changrong, & Watkins, 2018); however, many of the participants relied on others to help them with their needs or to make their decision. Many participants perceived that no one was helping them. They feel that they could not manage their own health and relied on others, such as nursing staff, to be aware of the medications they should take. They sought assistance from the facility's social worker for home placement; however, community resources lacked the funding needed to assist them. Not all of the participants were actively looking for jobs, primarily due to their disabilities. Some of them relied on their Supplemental Security income, which averaged \$735 per month; an amount that is insufficient to cover the cost of living in Southern California. They relied on others (e.g., family, friends, medical providers) to make their medical decisions; nevertheless, they did not follow the suggestions given to them. The following excerpts from the interview transcripts describes their reliance on others in their own words.

Participant 1 (P1) was in the hospital for several months. He did not explain the reason for his blindness; however, he relied on his sister to assist with his medical decisions:

P1: *Since I cannot see, she does all my stuff I'm suppose to sign and all that ... Well for one she don't have anything to do cause she's retired.*

Participant 2 (P2) suffered a stroke and was diagnosed with AIDS. His sister was in control of his finances. P2 was upset that no one could help him find an apartment and his perception was that his sister wants him to remain in the nursing home indefinitely. He expressed that he could control his finance, but feared that his sister would not support his independence. He was especially angry at the AIDS Foundation for not helping him find a home.

P2: *Yeah but I don't want to piss her off. ... my older sister is the one in charge uh gets my money so right here I pay like 24 hundred. That's all my social secure and pension comes here [nursing home] I get \$35... I smoke ... I'm sacred my sister won't come. You know what fucking pisses me off? All these organizations aids like buildings where they go to? They don't have housing for me know that pisses me off you know I can't get housing because I'm 58. I'm suppose to be 60 before they consider me.*

Participant 3 (P3) was homeless with wounds. He was able to live in the nursing facility because his insurance case manager helped to find him placement in a long-term care facility. He felt like the insurance could do burial placement for him, too. He relied on the help of others to assist him with getting off of the streets.

P3: *Yeah. I use to that place. I knew I was okay there. I mean for the most part. And then my nurse was going to pick me up. I have kind of a nurse that helps me out and she was taking me. I was trying to tell her, I said, look, I said, I know that I'm out here and this ain't better. I need some help. I mean I feel like everybody I've talked to has fall on deaf ears. I said, the longer I stay here on the streets. I know I picked me out here because I didn't want to go to East LA. I said, but there's some where or something, some body, a program, something that you know, because this is me being on the streets, is not beneficial to my health and so that they actually, she's picked me up and took me to my podiatrist, and she talked to the podiatrist about skilled nursing facility, this place. So he put it in a recommendation and they put in uh they put in a recommendation through my podiatrist and my primary doctor. So I went to another doctor, I forget the name of it. Oh, transitional doctor and he looked at me and evaluated me more closer and while I*

was sitting in an office. He was already trying to LA care state. This gentleman needs to be off the streets because his feet is that bad beaten ... said, "okay fine. Give me a couple of days to what we can do." I guess about a week later I was here. Just get one of those insurance companies where you pay them and they do it for you. So when you pass away, they you pay money as like they'll cremate you, you know, in other words, they build you what you want them to do Cremated and spread here.

Participant 4 (P4) had endocarditis and was in the nursing home for a 6-week course of IV antibiotics. He was able to walk with a four-wheel walker. P4 explained how he was getting Social Supplementary Income and was being discriminated against for his getting help.

P4: *... Since SSI and disability paid by my money. So, should make it a lot easier. And that a change I know over in the past like it's been a change in that the system for people with Social Security and all other stuff the past 20 years. You know, people have made it sound that you're you know, "oh you're a bad person you just gonna the milk the system. You just want free money." I don't want free money I paid in to it. I'm sorry it's not free and I think a lot people are kept ignorant.*

Participant 5 (P5) was a morbidly-obese man with wounds as well as being wheelchair-bound. He discussed how he got help at the store and relied on others to help him with his disability. He realized that the nursing home was the only place that would help him.

P5: *They have a bus here that picks up the people that are all on the list to go to Wal-Mart and then you can just go in here you have to push me in my chair cuz I don't walk very far without the chair as a result of someone pushes me down the aisles and tell them what I want to buy and then they push me over the counter to check out and they usually after that I'll head over the McDonalds part the store buy some food to eat right there. This is not a nice place I don't have anybody to help me or have a place to live so I have to stay in this place*

Participant 6 (P6) was also morbidly obese and suffered a right-hip fracture. He used oxygen for his COPD and explained that he could not go back to living in his parent's garage. He could not help himself.

P6: *... I said I can't even walk I'm not getting released until I can that way you know, if I can at least walk, I can help them clean the house, cook for him and stuff like that. I understood the reasoning. He was letting me say there, but they can't take care of me and*

living in the back. They can't even go back there you know. No guilt trip in the dark or something, I don't want to risk their lives over me.

Participant 8 (P8) was a recovering drug addict. He explained how he tried to help himself by going through the Salvation Army Rehabilitation Program, but he failed to report the use of prescription drugs. Therefore, he was kicked out of the program.

P8: *Yeah yeah you kidding me it's more work than recovery, you work you do classes at night. It is a pretty good program yeah although they kicked me out. I'm half way through it because I took pain medication when I was at the doctors because of my leg because I was in pain and stuff they kicked me out*

Participant 9 (P9) was chronically homeless and wheelchair bound. He explained how he was waiting for the social worker to help him find placement. He discussed how they were looking for a place for him. He could not financially support himself before he was homeless; therefore, he relied on his mother and grandmother to provide his housing.

P9: *I'm waiting on my Social Security and disability come and they are going to place me uh a independent care center place me in that and I can go for there whatever I'm going to be doing I'm going to do it there. I lost my job I lost my mother and grand-mother, the people I depended on for support.*

Participant 10 (P10) had two daughters. Because of his long history of alcohol abuse and his left-side, below-the-knee amputation, his daughters would not help him. He wanted to leave the nursing facility and was relying on the social worker to find him a placement.

P10: *Yes, first I would like to go home but they need to find me a place to home to.*

Most of the participants required some type of assistance; however, they did not feel empowered to make a change in their lives to break the cycle of homelessness. They were awaiting resources from the government and/or organizations that could help them find placement.

Lack of Health Awareness

A common theme among the participants was their lack of awareness to their health. Many of them did not understand their disease process due to a lack of communication with their health care providers in the long-term care facility. Many of the participants did not recall discussing an assessment of their health condition or any treatment plans with their providers. They did not understand nutrition, wound care, or addiction. They perceived that they were sicker after the hospitalization. When the researcher presented the POLST to the participants, they were unaware of what they signed and did not understand terms (e.g., cardiopulmonary resuscitation) and did not understand that full treatment could include mechanical ventilation, artificial nutrition, or dialysis.

One common topic among the participants was the lack of communication between the health care providers and the participants. Some stated they were unable to see their doctors for months and were unaware of their health status.

P2 *I go to my doctor every 3 months for lab test but my doctor tell me nothing but just to stay here.*

P5: *You know I haven't seen a doctor [at the SNF] at this place for 9 or 10 months ago seems like they don't come in the room and talk to me so I don't know who they are like that.*

P8: *No it's been a year now but you know it was just swelling it wasn't painful in the day when I'm pushing a cart I felt like a twisted a muscle behind my thigh that created the infection so yeah I haven't got a straight answer from the doctor exactly what this is all about that's what I'm looking forward to hearing. The nurse practitioner said I had sepsis you know which is a viral type infection bacterial infection but I'm suppose to see a bacterial infection specialist today yeah so hopefully he shows up.*

P9: *They didn't tell me nothing.*

P13: *That I don't know, all I know is that me being homeless uh long period of time I'm that doctors said that when they brought me here I was really drunk [when ask about health status from their doctors] uh ... sometimes but they don't really ask me about my health.*

P6 discussed the lack of communication among the nursing home and the health care providers, especially with follow-up after his hip surgery. He struggled to understand why he could not walk. He was frustrated that he could not go to his original primary care provider.

P6: *The doctors here, first time I see you hit one of them. He comes to be a couple of questions and it goes, okay, bye, I'll see you in 4 months. Remember when I've seen them a couple of times. I've seen the assistant more than I have seen the real doctors. The doctor's assistant now, but before I wouldn't even seen them. I have my own doctor. Oh they wouldn't let me go to mine. At first she was different, run by a different company then, but you said no. They call that double dipping. We got a doctor here and you know you're not allowed to do that.*

He didn't check what the other doctors. Is it anything about my case or I'll be put. You know he did the surgery; he didn't ask, I didn't even talk to him. He had no correspondence no medical records set. Nothing like that. He just figured all I can take it around, around about a month or two, you asked me, well lawsuit come, you can't walk. He says well I've done everything I can do. He goes I really suggest you know you have to go back to your primary care doctor. Have them give you a x-ray. Maybe you have a broken back.

P1 explained how he was in the hospital in the intensive care unit with intubation, unaware of his surroundings. The last thing he remembered was that he was supposed to go to the doctor, but he was never seen until he was hospitalized. He stated that he did not take any medications prior to the hospitalization.

P1: *They say "he don't know how he doing it, he don't, don't where he at" and so, "poof" I guess doped up I didn't know where I was I didn't that's a scary feeling. And then when you finally wake up out of that you say "damn, where am I?" You need to look around you didn't know what happened. But I knew I was getting sick though. I was started slowing down. But I went to the doctor they gave me appointment, but I never made it to the appointment.*

Makes you try to pull IV s. I mean the stuff that you might not be there but you could feel it. And that's what my daughter said I was doing. I kept pulling the IVs out trying to pull the tube out so they can do what they had to do. Strap my hands down. And that I didn't work either. She said, "I don't know how you did it. I'm sit over there watching you and your hands just kept moving. Then it went up under the rail like this and come back on the top then went back under. I next thing I know this hand was do it like this." Yeah I never take no medication.

P3 discussed the angiogram. He thought that it would be a simple procedure, but he ended up with a toe amputation instead and was not aware of what he was signing in the procedural consent form.

P3: *So anyways, they call in a procedure and then they brought me the papers to sign for procedures and said we're going to go out there and cut it out. All of a sudden I'm looking at the [inaudible 15:42]. Here's another paperwork to sign too and then they said, amputation. I go "wait a minute, what's this amputation?" They said "we don't know how bad the infection is, when we get in there, and because don't want to point it out that we'd have to amputate your toe. We'll put you in anesthesia, sign the papers, put you back [inaudible 16:08], and said I have seizures very tricky thing, which I do know about that. So I said, okay and then I go well, am I going to have a [inaudible 16:18] and they said, we don't know. We'll find out when we get in there because we just can't tell how bad the infection is. So I woke up with toe that looks like hamburger, but I did. It was almost healed. Okay.*

P3 also discussed the types of food that he was offered and the types of food that he could afford. It appeared to the researcher that he had poor access to food causing his morbid obesity and swelling in his legs.

P3: *I go across the street to 7-11 and I handle them, I buy hot dogs or whatever or burritos or sometimes people would give me food some people would come by and say "what you do you need? You need something to eat?" I'm like "yeah so we'd go and buy me a sandwich then there's a pizza place across the street. They helped me out give me credit. They've been there so long that they kind of knew, "okay well he ain't going anywhere, so okay. I'll give him credit for the pizza" and I pay it back in the next couple of days.*

P4 discussed how his health had deteriorated and how he needed pain medication. He has been using pain medication for over 2 months, but denied addiction. After 2 months of being in the hospital, he continued to experience back pain.

P4: *That's was it when I got here I could walk around I've been trying to get around even then I've taken a little, I've had friends coming to take me out and we go out to lunch or whatever. And even then after about 2 hours, 2-3 hours I come back I'm sore I'm tired. Not just like walking to a car to a desk. "Oh let's go over to the food for us so I can get some stuff" And walking in there and come out. So just walking and shopping for 30 minutes so you know. I was sore afterward. That enough that I had to take a Norco, which is which is another problem, like I don't like taking narcotics. I don't like taking pain pills period. I'll take them if I have to I don't like taking narcotics*

P5 discussed how he could not take care of his leg wounds and relayed how it could get worse without visiting the wound clinic. He did not take care of the wounds himself.

P5: *Uh I just guess they're stabilizing in otherwise they are not getting real real bad but if I didn't make those appointments blisters would start breaking out of my legs and they would be real bad. That's why I have to maintain those appointments every week.*

When discussing full treatment, such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and dialysis, many of the participants stated they did not know what these terms mean. The following statements clarify that participants lacked understanding:

Mechanical ventilation.

P5: *Yeah you put a little tube in your mouth for about a minute or 2 whatever. Oh I had breathing machines for a while but I'm not on attach. I don't have tank that I carry with me I don't need one where I can breathe fine without using a breathing machine.*

P6: *Well, most of the time since I've been sick of using almost continually day and night, normally I try to stay off the daytime, wean myself off because you get to where you feel like you can't live without it. IF you take it off, you feel like you're getting the oxygen feel like you are. It's a crutch that you lean on it too much. I don't want to get that, so try to keep it just for sleeping at night or when I'm exercising or doing wall all the way down to use the chair here.*

Yeah I don't know much about it I don't like it

Cardiopulmonary resuscitation.

P8: *It's to pump the chest I don't know enough to say.*

P9: *It's when they put you on a heart dialysis and see if your heart is beating and stuff. I don't know what exactly what it means.*

Artificial nutrition.

P9: *Artificial nutrition? Is it some kind of drink?*

Dialysis.

P1: *So they got a new program where just like the high blood pressure straps they put on on you. The havin' them all over your body. And they hook to a machine and expose your right leg or body parts which are hard. They hook it up to a machine another one somewhere else and it circulates like a pacemaker.*

P5: *I don't have that problem my kidneys are okay. I would like to find out about all its about and how hard it would be on my body and everything like that before I automatically say I would do it.*

P6: *I heard that once you get on it you don't live very long afterwards it's no good. I've know a guy that was on it and he died, my stepmother was on it for a while, but then she got better, so I guess it ain't the end of the world if you start to do it because she got over it somehow.*

Technologies keep always coming up with something new that keeps me alive. As long as they keep all wires, you know what ever.

Yearning for Home

Most of the participants discussed living on their own. They expressed their perceived independence because the nurse aids did not render much assistance. Some of the participants tried to live on their own after being in a long-term facility.

Unfortunately, they had to return to a different long-term care facility. They appeared to be unaware of their physical disabilities; however, they continued to dream and to hope that they would one day leave the long-term care facility permanently.

P1: *I'm trying to get my own place, I always been (by) myself.... Trying to find a place to go.*

P2: *I just wanna to be free you know but you know my sister doesn't like me to be free you know. Because I can take my medication and bathe myself ... Well it's hard but I brush my teeth and all that ... They just make my bed that's all They take me on a shower chair and they bring me to bed and they let me dress myself ... I look for apartments but sister doesn't want it ok because in Social Secure I get \$,2100, I can live on that but my sister.*

... My sister and I had like bad credit she talks about that maybe it's true because I can set it out about my money and make like \$1,000 with like a house or apartment who care if it's not fully functional like only has a stove that's all I need yeah buy things at when I can so.

... And all these and social services tried to help me find places for me but nope no dice. Only 60 and over ... yeah I told her that I have someone for medication I have a nurse and I got one to clean and cook that's all I need that's she afraid I might go down where that same path now I don't go through the path.

P3: *I've been watching you know like the last Alaskans and buying in Alaska and seeing that. I like to go to maybe not to Alaska that I could go up in the mountains and just kick it for a while. Maybe have a cabin. I mean I don't think I could do like how those hard-core guys are doing but I'd like to go up there, you know, go traveling and go in the*

mountains. Me and my mom always like to go to the mountains quite a bit ... everywhere San Diego mountain, San Bernardino, the beaches the beaches in the mountain so it doesn't really matter. We camped out on the beach before. I know I kept, well roughly I kind of marking the days but I mean for whatever I'd have left, just enjoy and have fun. Try to have fun without bothering anybody. You know just have fun. Yeah. Just doing my own thing don't worry about, you know, helping people out in the past, doing this and whatever blah blah blah just like trying to do it for me.

P4: One of my concerns is that when I do get out and I'm trying to find a place to live if there is, is to have her [dog] with me. She's all that I've known how we're live that all she's still around you know.

P5: Well the guy of the charge of these homes well, he had 6-7 of these homes in line there in R _____ San B _____ he was trying to find people to live in those homes call board-and-room type of arrangements. And so I agreed to go but when I got there I found that [chuckles] they didn't even have low thresholds so I couldn't get my chair into the house bricks were all in the front and back and I had to have help lifting me up to get me into the house and when I got into the house they didn't even have a TV that worked I couldn't get out in-and-out of the bedroom he had for me. When I had my chair somewhere and the bed was on the floor and I have to be able to pull myself up to be able to get out of the bed. So that didn't work out too well. I couldn't even go the bathroom the chair didn't fit through the bathroom. I told him finally he had taken my money which would have been \$600 monthly payment for being able to stay there finally after 3 weeks it was working out and I needed to be sent someplace else so I told him about a motel that would take me, then I found out that the motel didn't want me either so then I was going around to a bunch of motels and finally I landed in the hospital again. From the hospital that time they sent me to Arlington Gardens which is a pretty nice facility although you can still wait for a long time for service there like you can here and so I eventually left A _____ Gardens after 5-6 months then they brought me back here v _____ I guess I been here now for 9-10 months.

There was something that I was doing when I was staying at a motel. At a Motel 6 for a while. I was actually paying them weekly rent to have the room and they put me in a handicap room that had a low threshold so I can drive the chair in and out of the room anytime I wanted to. I can get in and out of the bathroom okay. And off and on the toilet and everything then I take care of everything but ehh.

P6: I'm trying to get on that program thing if I ever get to the bottom of their list or apartment. [Okay. That's your goal, right?] Yeah. That's my goal is to get my own place enough to. I don't need to be here, but those voices I can get help real quick. There's people always watching out for you because you got neighbors that are all your, you know, pretty mature situation. We're all on their last leg. So they watch out for each other. Hmm. Some of them may have a handicap facility to make it easier for you to live in a regular apartment.

P8: I want things in life, first insurance, a house I want to comfortable live enjoy with laughter with the last years of my life which who knows how long that's going to be here. look over here with my roommate David here is 85 sharp as tack and still getting around well I can die tomorrow who knows but to have things in this world you have to pay for it so I need to go to work it will happened and soon as God says.

P9: *No I was on the street, I had a sleeping bag, I would have a favorite park that I would go to that I would have no trouble sleep if I wanted to but I had a sleeping bag, I had equipment that you know accommodated to the weather one for spring and fall. And I have no problem with that it had a roof on top it, a picnic area if it rain I wouldn't get wet So I was living like that for years.*

[If you didn't break your hip, would you still be ok living like that?]

Yeah. It didn't bother me, I stayed there kept myself clean and in good health.

P10: *Get out of here. Or maybe with my daughters or something. I really don't know but I would like to be out here.*

One might question whether a homeless person would consider the long-term care facility a home. To these participants, it appeared to be a holding place until someone or something happened. For many, this type of residence was not a choice, but rather a necessity as they returned to a state of health and well-being.

Locus of Control

Locus of control has been defined as one can control the outcome of his or her life (Sargent-Cox & Anstey, 2015). Locus of control has been identified in two forms: external and internal (Sargent-Cox & Anstey, 2015). An external locus of control is an outside factor or fate that controls one's life (Sargent-Cox & Anstey, 2015). An internal locus of control is when the person believes that one controls one's own life based on one's actions (Sargent-Cox & Anstey, 2015). Most of the homeless participants had a high external locus of control; they felt that external forces, such as a hospitalization, lack of job opportunities, disabilities, or other people caused them to stay in long-term care facility.

Internal locus of control.

P1 had been living in the nursing home for the past 8 months and felt that his recovery was motivating him to walk on his own.

P1: *I still want to see if I can do it on my own. I mean like I said, don't get me wrong I do appreciate all the help everybody's given me I don't know where I'd be without it, But I still want to see if I can do it ... Yeah I've had it for a long time you know and all of*

sudden now I'm in my 50s things kind of go to the short cuts. I'm not really thrilled. I mean I'm not thrilled with my situation. I mean I could of done thing to prevent it. Probably work more than what but what is. So, but I'm here now. So got to make the best what I can do.

P1 has tried to help the other nursing home residents return to their former, functional independence.

P1: *We like the way you'll be pushing us you're gonna be our new what they say our new coach ... don't hang wanna get up and do your therapy. You ain't no get to this part. Don't might-that wheelchair hurt your butt I'm trying you. You get out of the wheelchair at least to a walker... I don't need this walk. I'll walk walk around the hospital without it. I shake my leg and it's done there for a minute and go back.*

P2 describes that he had control on how he was going to die, living with AIDS, and accepting his debilitating disease.

P2: *But they have this new form with your medical doctor make that decision for you you can die*

Yeah, if my sister can't decided than I suicide. If my sister can't make that decision I will tell my doctor... oh but I haven't discussed it with my doctor.

P5 discussed the nursing facility's aids, how he would ask for help, and how he would try to be independent. He felt that the aids did not respect him because he was outspoken and independent.

P5: *I guess I been here now for 9-10 months. And this was no better than before the first time. These homes are not any good because it takes so long to get help when you need help and lot of times they won't even answer their call buttons when your pushing the button to get help or something. So I learned to do everything myself for example I can get up out of this chair I have to grab onto something so I don't fall and I can go over to uh bed and get in and out of the bed. I can dress myself. I take my clothes off. I can go to the bathroom by myself without anyone lead me into the bathroom. I can do most everything by myself even then I still don't get any respect and try to make the job easier for them. So they don't have to do a lot work with me. But I still don't get any respect because a lot of times they take 3-4 hours come in when I need help.*

P5 also perceived that he had control of his finances; he refused to sign over his government assistance money to the nursing home. He collected antique car toys and stored them, both in his room and in rental storage.

P5: *I guess the insurance companies are paying for my stay here 'cause I'm not paying for one penny of it. If they get to the point where they are going to start charging me, I'm going to refuse to do it. Because I have toys that are in a facility, I mean a storage and I don't want to lose those.*

External locus of control. P2 discussed how his sister and doctor prevented him from leaving the long-term care facility. He felt that he was *independent enough* because the nurse aids would tussle to have him in their assignment as he is low maintenance.

P2: *Yeah yeah because my doctor said I'm ok to go but my sister doesn't want me so yeah. Can I tell you? I don't like this place*

No nurses get excited when the nurse aids gets me because they don't do nothing for me. She's happy she got me.

P2 explained the untimely death of his significant other. He was not prepared to live on his own. His significant other supported him financially.

P2: *Yeah because ... [cries] drug overdose and uh ... heart attack. So I regret that I didn't tell him to stop, I did tell him to stop but he won't. He won't listen to me he said he would but he didn't and that's fucked up. I'm left without a house and I had to go to my sister and I had him take care of me. I didn't know what to do.*

It was free because fucking my lover broke my contract or will, because he didn't notarize the godmother told me to leave. You know all my clothes was there and furniture.

No I had to come here. I woke up and found myself here. They told me I was only here for physical therapy but bullshit [laughs] bull shit I'm still here.

P6 was living in his elderly father's garage when he broke his hip, which hampered his ability to walk. He blamed old age for his lack of independence.

P6: *Yeah it must be a crazy thing. When you're young, you never think you're going to get old. Do you think about it like that so far? And you just use, put in the trashcan and just keep on enjoy life if you don't prepare for it. We started. Never thought I'd get that old probably.*

P8 discussed how he could not find a job because of his past conviction and incarceration. He felt that he had no control of his life because of the crime he committed; one he perceived was not severe.

P8: *So I did my time, I don't mean trouble or nothing. But now I viewed to the general public as a monster. Well you see aggravated robbery and kidnapping on someone's record you automatically think the worst of that person so as you can imagine I was a*

contractor for a couple of decades with my own business and I uh now I can't get a contractor job license to do my what I love to do which is construction. I've done it all my life, so now I can't provide for myself. It's very difficult to get a job with those charges on me someday. Talking about your pain and stuff it does help yeah talking someone that you feel comfortable with.

P9 shared how being convicted for driving under the influence caused him to lose his job as well as losing the ability to find another job.

P9: *It made me feel good it made me sleep good I'd go to the library and watch movies with movie player yeah rent movies at the library and watch it in there that was my hobby then.*

When I got laid off all I got was unemployment and insurance for a while and it ran out and I was caught for drunk driving and it wreck my driving record and you know you had to have a good driving record if you want to be a bus driver because some company won't take you and especially drunk driving they won't hire you

P13 discussed that how she did not seek help from the homeless shelter because of her past experience of being raped.

P13: *Well, they tried [long pause] but I just don't get a-long [stutter] with the ... um the men.*

It's ... It's more like at the men [long pause] they try to pick up on me ... but not only me but the other girls too.

Perception of Death

Most of the participants in this study perceived a good death as either quick or passing away in one's sleep. The perception of a bad death varied among participants and involved pain, trauma, or dying at a young age.

P1: [Perceive good death] *I guess in my sleep.* [Perceive bad death] *Pain.*

P2: [Perceive good death] *I just want to go like my mom and dad just go fast. I don't want to hurt no suffer.*

If I'm on the tubes and everything else, and there's no foreseeable way for me getting any better, except for those tubes and respirators, no unplug me. But if there's a chance I'm going to get better and maybe limited productive life okay. But there's no chance of me living a productive life where I got to be taken care by people, no I mean you know, it depends. In home care or something like that yeah, but I don't want to be ridden. I still want to be able to do somethings on my own

[Perceive bad death] *I would say without pain with pain because I watched my mother and father when they passed away, they were in pain and that stuff. Because that may be*

kind of questioning God every once in a while. Maybe you got a bit because God is all-knowing, all-seeing and all-caring all-loving. Well if he's all-loving, all-knowing, all-caring, all-seeing then he knew my mom were dying, but first with the pain, it was prolonged. God knows it. He eventually is going to get my mom and yet he's a loving god, and he is a knowing god, why put them to pain, why not just take them now? What's the sense putting them through pain for longer, when you already know these things that you already know that my mom and are coming to you. So already know these things that you already know that my mom and dad re coming to you. So why? What I'm saying? I don't question God. I have questions for God.

P4: [Perceive good death] *Dying, dying, dying quietly in my sleep. You know, would be nice. Yeah, that would be - you know I would - I would - I like - I would like to death could be a thing where you know you know that would be a nice death. I mean you know heart attack, whatever, it's gonna happen somewhat.*

Mm, yeah the fear of death is everyone has, but my concern really is not - 'cause when I'm dead, I'm dead. My mother have the same call, she goes, "When I'm dead, I don't care what you do." But she wanted to be cremated, we cremated her. I told my friends you know, if I die, you know, put me in a boat, Viking -- burn me in a Viking boat off the coast.

P6: [Perceive good death] *Dying must sleep as my great-grandmother always wished for when had you be over a hundred years old. She died in her sleep. That's how she wanted to go. That was a good way to look at it. Way I'd have the same wish. Granted I would do the same thing.* [Perceive bad death] *Ah ...Get burned alive or something.*

P7: [Perceive good death] *Go in your sleep I guess.* [Perceive bad death] *Get shot or stab.*

P8: [Perceive good and bad death] *No no I wouldn't and that when I'm going to have my son buddy going to get a much of heroin so I can just OD and go to sleep and put my family through the agony to watch me deteriorate.*

P9: [Perceive good death] *Uhhh.. I don't know natural causes due to old age that's the way I would see it* [Perceive bad death] *Young age when you don't deserve it.*

P10: [Perceive bad death] *I think it was kind of painful.* [Perceive good death] *You know what I don't know that to say about that what's a good death, but you know a peaceful death when you don't feel nothing.*

P11: [Perceive good death] *Like smoke cigarettes before I die and die in my sleep.* [Perceive bad death] *I don't know but if someone got run over.*

P12: *Uh, natural death.*

P13: *Drunk*

Summary

In this chapter, the participants demographics were displayed. Thirteen people were interviewed about their perception of advance health care planning, especially with

the POLST and their perception of death. During the analysis phase, five themes emerged from the data: lack of self-efficacy, lack of awareness of health, locus of control, yearning for a home, and perception of a good or bad death. An extensive table supporting this analysis can be found in Appendix E.

The first theme identified was lack of self-efficacy. Most of the participants relied heavily on others to help them, including their health, finances, and home placements. They perceive that they could not help themselves or be self-sufficient on their own. The participants thought the long-term care facilities were responsible in assisting them to find placement; however, social workers lacked the support from the community. Participants believed that they would not receive help from with family members due to previous or current drug addictions.

Aid that was given to these participants was not sustainable. Organizations, such as LA Care or the AIDS Foundation, could not provide unlimited housing funds. As most of the participants felt that they could not find work due to their disability and lack of education, aid needed to be indefinite.

Lack of health awareness was the second theme identified. This lack of awareness manifested in the lack of communication among the health care providers and the participants and the researcher witnessed the lack of understanding about one's own treatment. Participants believed that they were healthier before coming to the long-term care center. They lacked an understanding of their disease process and how diet could exacerbate that process. Most of the participants did not know about advance health care planning or the reasons for a POLST form; however, some participants did remember signing the document.

The third theme was a yearning for home. The participants did not perceive that the long-term care facility was their home; only a placeholder. Many had tried to leave the facility, only to be returned to a different facility. Living in a long-term care facility was not their choice; it was a necessity.

The fourth theme was the locus of control. Most participant exhibited a high external locus of control where an illness or an accident required admission to a long-term care facility. Most feel they could not leave the long-term facility because family, health, or trauma would prevent them from living a full life.

The last theme noted in this study was the perception of a good and/or a bad death. Many of the participants perceived a good death as dying by falling sleep and without pain. Conversely, the perception of a bad death could be described as “when you don’t deserve it.” Many of the participants also equated a bad death as one related to trauma or dying at a young age.

Chapter 5

Discussion

This chapter will review the findings from this study, compare results to similar research, and discuss the strengths and limitations of the study. Additionally, implications for future research and policy will be examined.

Reflection of the Findings

The population demographics in this study were similar to the literature review on people who are homeless; homeless population have been hospitalized prematurely when compared with the general population and most were considered older adults (Henwood, Byrne, et al., 2015; Kimbler et al., 2015; Wadhera, Choi, Shen, Yeh, & Maddox, 2019).

The participants in the nursing home could not be discharge without a safe plan; for some, they either stayed in the long-term care institution or chose to live on the streets. The participants in this study tried to live on their own but were unsuccessful due to their disabilities. The community and the social workers in the long care facility had a paucity of resources. In this study, there was a profound theme of “yearning for home,” and “locus of control.” The participants in the study did not consider the long-term care facility as their final home but as limbo as they waited for their “true home.” The theme “locus of control” provided insight on the mental and external barriers that the participants described for their stay in long-term care facility. Similar to the literature, most of the people in this study who were homeless had a drug addiction history that many perceived outside of their control; an external locus of control (Page et al., 2012)

The perception that homeless people were content to live in a long-term care facility appeared to be untrue. The majority of the participants in this study were dissatisfied with their life situation. These homeless residents were still searching for

affordable housing, but lack assistance amongst themselves and community. All of the participants appeared to have requested services from organizations as well as government assistance with housing. The state of California recently passed Assembly Bill 1618 (2016) amending the Mental Health Services Act (MHSA); a state income tax of 1% to provide affordable housing for the homeless (Palta, 2017). The effective use of these funds has met resistance from various neighborhoods that decry, “not in my backyard” (Replogle, 2018, Chapter 1). The major apprehensions among the neighborhoods were how the presence of affordable housing would affect property values, safety, drugs, and proximity to schools. Replogle (2018) discussed the discerning lack of community support particularly directed at housing homeless individuals who were disabled.

A prospective, longitudinal, 2-year study by Fuehrlein et al. (2015) followed homeless people’s housing status and their associated cost of mental and health care. Twenty-three agencies serving homeless people provided cost data and the types of services utilized (e.g., medical, mental health, substance abuse, homeless shelters). Fuehrlein et al. reported that people housed longer had increased medical costs. Paradoxically, those with mental illness who were housed earlier in their homelessness used less mental health services. The study hypothesized that the housed participants with medical issues were more likely to utilize medical services due to increased accessibility

There is limited research on homeless people living in long-term care facilities. A cross-sectional, qualitative, descriptive study done by Chamberlain, Duggleby, Teaster, and Estabrooks, (2019) utilized interviews of long-term care staff and examined public guardians’ interaction with homeless persons living in long-term care. This Canadian study described homeless residents as unbefriended residents, who lacked the capacity to

make decisions and had no health care agent. The important findings from this study showed that unbefriended residents had minimal social support and tend to have more aggressive care towards end of life.

Currently, no research on the perception of advance health care planning among homeless persons currently living in long-term care facilities could be identified. The demographic characteristics in this study were similar to a study by Kushel (2017) using a secondary data set from the Health Outcomes in People Experiencing Homelessness in Older Middle Age (HOPE HOME) study; a survey of 350 middle-aged or older, homeless adults. Sudore, Cuervo et al. (2018) reported the median age of chronically-homeless individuals was 59 years. They identified that chronically homeless older adults were less likely to complete an advance health care directive. In addition, less than one-half of this population had an identified health agent. Sudore, Cuervo et al. reasoned this decrease in advance directives was due to the social isolation that chronically homeless people experience. Another explanation could be the focus on basic necessities, thereby avoiding end of life discussions. Findings in this study demonstrated that most of the participants did not have an advance health care directive and less than one-half of the participants had social support; similar findings to the Sudore, Cuervo et al. study. When asked about their understanding of the POLST form, many stated they did not have enough knowledge about the legal document; nevertheless, they remembered signing a pink document.

Initially, the study was to examine the perception of advance health care planning among homeless people in long-term care facilities; however, the interviews guided the researcher toward the perception of the individuals who were chronically homeless, their perception of their own health, and their willingness to leave the nursing home one day.

In addition, the study explored the lived experience of the chronically homeless individuals' initial admission to the long-term care facility and the causal nexus of leaving against medical advice, suffering a medical emergency, and returning to same type of long-term care institution.

Locus of control comes from the Attribution theory, which was first introduced by Heider and later advanced by Weiner (2018). In this method, people describe the behaviors of themselves or of others to find possible explanations for their behavior (Weiner, 2010, 2018). The theory purportedly promotes motivation in people or at least explains reasons not to change. Attribution theory has 3 elements: locus of control, stability, and controllability (Weiner, 2010, 2018). As explained in Chapter 4, locus of control has two subcategories: external and internal. Internal locus of control is when people believes that they themselves can change their situation (Sargent-Cox & Anstey, 2015). External locus of control is when people believe that external forces, such as illness or other people can change their situation (Sargent-Cox & Anstey, 2015). According to Weiner (2018), Attribution theory suggests that emotion can be quantifiable. Figure 2 below illustrates how three elements intertwine: locus of control, stability, and controllability.

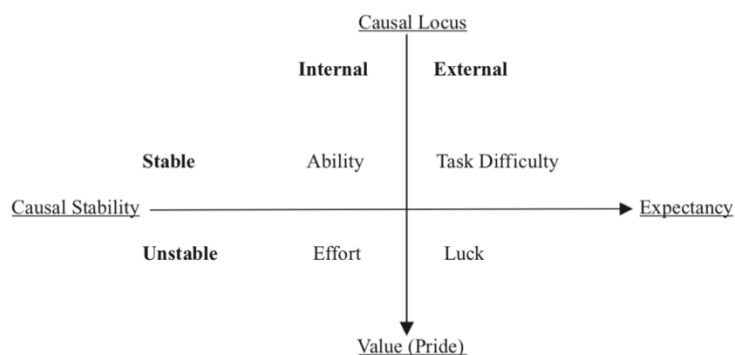


Figure 2. Elements of Attribution theory, from “The development of an attribution-based theory of motivation: A history of ideas by B. Weiner, 2010, Educational Psychologist, 45(1), p. 32.

A study by Lancot, Bergeron-Brossard, Sanquirgo, & Corbiere, (2013) tested Weiner’s Attribution theory among persons who were unemployed and had psychiatric disabilities. These authors used a longitudinal approach by collecting data at two phases: at the registration employment center and at the 9-month follow-up. For the locus of control, they asked the participants to explain their reason for un employment. From this, they were able to categorize the responses into the themes of internal vs. external control. The measurements they used were socioeconomic demographics, a brief self-esteem scale, and a brief symptoms inventory. They recruited 126 participants for the study and reported that men had a higher external locus of control that was uncontrollable.

The participants in this study described their poor health, addiction, family, or incarceration as preventing them from having a home. Most of the participants had a misconstrued perception of the stability in their health, thinking that their chronic condition would change. The key factor in this study was that the participants perceived that they could or could not control their behavior in order to change the homeless status. This author plans to explore the application of Attribution theory to homeless people living in long term-care in future research.

Study Limitations and Strengths

The major strengths to this study were the paucity of research on this topic and the traditionally-limited access to this subgroup of homeless individuals. As a population, homeless individuals have been distrustful of health care institutions. Some may also be guarded about their circumstances. One quality of this research study was the trustworthiness demonstrated by the participants towards the researcher after the social

worker's introduction and high recommendation. A profound finding of this research was the participants' incomplete comprehension of the POLST form and their lack in understanding the term, full treatment. This population would benefit if the study was replicated to verify the themes. The study does reflect other studies on the perception of a good death, as most participants wanted their end of life to be pain-free and in their sleep.

One limitation of this study was that it could not be generalized. As a qualitative study, this research focused on the lived experiences of homeless persons currently residing in long-term care facilities and their perception of advance health care planning. All of the participants were required to speak English to be included in this study; however, future studies could evaluate the similarities and differences in the perspectives for participants from other cultures.

Implications

A common perception, including among health care providers, is that the long-term care facility is a permanent placement. This perception was not shared by the participants in this study. They expressed that they wanted to control where they lived and how they lived. Due to their lack of self-efficacy and lack of self-awareness about their health, they did not understand certain functional capabilities. Many of the participants in this study could benefit from assisted living where they would have supervised care, such as help with their medication, meals, transportation, and some assistance with their activities of daily living. Social services and case management would need a coordinated evaluation of the homeless person's ability to be self-sufficient in the community (e.g., assistance obtaining employment).

A potential model of a program for these participants was depicted by Brown et al. (2013) at the Hearth Outreach Program in Boston, MA. This program assists

homeless older adults with a disability in finding permanent housing and providing health care and mental-health support. The Hearth Outreach Program utilizes case managers to assist their clients with applications for subsidize housing. Once housing is secured, case managers continue their support for the member during their housing period. The Hearth Outreach Program operates 196 permanent housing units in Boston, MA with multiple levels care, including board and care, assisted living, and apartments. Their interdisciplinary team conducts and arranges goals specific to their clients' needs, including the need to extend their time in the apartments. Unfortunately, this program lacks a cost analysis, feasibility study, and has not been replicated elsewhere.

According to the National Academies of Sciences, Engineering, and Medicine (2018), the types of barriers to permanent, supportive housing for the chronically homeless population include structural-, community-, and funding issues for this population. The committee concluded that there is a lack of supportive evidence demonstrating that housing improved health outcomes. Likewise, there is lack of governmental and organizational support, as seen in the AIDS Foundation, to assist with housing. This organization recommended a future research model to include another 2-year prospective longitudinal study of pre- and post-interventions with cost analyses. The National Academies of Sciences, Engineering, and Medicine report revealed how complex it was to provided effective housing to homeless people.

The researcher recommends an intervention to address issues with locus of control. For homeless people admitted to long-term nursing facility, those identified as possessing a high external locus of control, providing cognitive behavior therapy could improve and elevate a sense of internal locus of control. High internal locus of control might lead to improved self-efficacy, both in mental health and medical health (Price et

al., 2012; Sargent-Cox & Anstey, 2015). An example of a tool that could be administered at the long-term care facility would be Rotter's (1966) internal-external scale. This instrument is a 29-item survey that provides a paired statement; the participant opts for one of the statements (Wang & Lv, 2017). Each statement indicates either an internal- or external locus of control response. The highest score indicates external locus of control and the lower score indicates internal locus of control (Wang & Lv, 2017). The reliability of this scale is 0.7 and can be used in a long-term care setting (Wang & Lv, 2017; Valecha & Ostrom, 1974). This may provide insight into predicting success with long-term housing.

Health care providers ought to be able to spend the time needed with the homeless population while discussing physician's orders for life-sustaining treatments. These discussions are not a one-time documentation, but must be addressed periodically, particularly for homeless persons with multiple co-morbidities. Realistic goals and expectations for their health should be to be established. Most importantly, while providing informed consent for treatment, the risks and benefits should be discussed each time. Some of the participants were ill-informed about their course of treatment and surgery. The participants in this study verified that they had seen the POLST form; however, most vaguely remembered signing it. As nursing homes are required to have a POLST form in the chart, it is imperative that adequate education be provided by the social worker at the long-term care facility. Five of the 13 participants (38%) in this study did not have a health agent. To most, the POLST form was another piece of paper they were required to sign and it is unfortunate that they did not comprehend the meaning of this order. In the study, participants claimed they had never seen their physicians in the long-term care facility; some spoke of an "assistant." This might indicate that the

participants were followed by an advanced practice nurse or physician's assistant; a level of care that would be crucial to this population considering the lack of primary care services available in this population. Also important would be more care coordination within the homeless population, such as a case manager representing the medical group, so that unwanted and unnecessary treatment could be avoided.

Conclusion

"People love to say, "Give a man a fish, and he'll eat for a day. Teach a man to fish, and he'll eat for a lifetime." What they don't say is, "And it would be nice if you gave him a fishing rod." That's the part of the analogy that's missing."

*— Trevor Noah, **Born a crime: Stories from a South African childhood***

The barriers to overcome homelessness in California are intensifying. Older adults appear to be most affected with the lack of affordable housing and barriers to obtaining jobs, health insurance, and mental health services. Some chronically homeless individuals develop geriatric syndromes earlier than the general population and, at times, feel forced into long-term care facilities. Many of them entered the acute-care hospital not only for their health, but for financial assistance as well. The current health care model is not sustainable to provide care for this growing population. Long-term care facilities are ill-equipped to find placement for their higher-functioning, homeless residents. Research is needed to create models of care specifically to assist transitioning homeless people from long-term care facilities to independent communities. Homeless people lack fundamental skills to provide self-care. Health care providers need to identify high risk, homeless persons and individualize plans by using a multi-disciplinary approach; this may include case managers, social workers, rehab, and/or mental health workers. Programs need to be initiated and evaluated for effectiveness. To assist homeless people in housing is to understand their stages in life. The serious lack of communication within this population and with the health care community regarding

advance health care planning was particularly poignant with the POLST form. Nursing science and health care providers need to rise to the challenge of providing more effective, holistic, and individualized approaches of providing care for this marginalized population.

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Appendices

Appendix A. Institutional Review Board Approval

From: irb@san Diego.edu
 Subject: IRB-2018-353 - Initial: Initial - Expedited
 Date: March 12, 2018 at 10:44 AM
 To: [REDACTED]



Mar 12, 2018 10:44 AM PDT

Janice Woods
 Hahn School of Nursing & Health Science

Re: Expedited - Initial - IRB-2018-353, Perception of Advance Healthcare Planning in Homeless Persons currently living in Long-Term Care

Dear Janice Woods:

The Institutional Review Board has rendered the decision below for IRB-2018-353, Perception of Advance Healthcare Planning in Homeless Persons currently living in Long-Term Care.

Decision: Approved

Selected Category: 7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Findings: None

Research Notes:

Internal Notes:

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited or exempt review at any time.

Sincerely,

Dr. Thomas R. Herrinton
 Administrator, Institutional Review Board

Office of the Vice President and Provost
 Hughes Administration Center, Room 214
 5998 Alcalá Park, San Diego, CA 92110-2492
 Phone (619) 260-4553 • Fax (619) 260-2210 • www.sandiego.edu

Appendix B. Informed Consent Form

Institutional Review Board

Research Participant Consent Form

For the research study entitled:

Perception of Advance Healthcare Planning in Homeless Persons currently living in Long-Term

I. Purpose of the research study

Janice Woods is a student in the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a research study she is conducting. The purpose of this research study is: to understand lived experience of the homeless persons living in a long-term care and their experience with advance healthcare planning.

II. What you will be asked to do

If you decide to be in this study, you will be asked to:

Participate in a private interview about your experience in advance healthcare planning
You will be audiotaped during the interview.

Your participation in this study will take a total of 60-90 minutes.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day:

Los Angeles County Department of Mental Health at 1-800-854-7771, or the researcher can request your nursing facility to consult with psychiatry and psychologist.

IV. Benefits

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be knowing that you helped researchers better understand homeless person living in long term care and his/her perception of advance healthcare planning

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

If you participate in the study, the researcher will give you a **momentary compensation of a \$25 visa gift card** will be given personally to you.

You will receive this compensation even if you decide not to complete the entire interview session

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care, or your employment or grades. **You can withdraw from this study at any time without penalty.**

VIII. Contact Information

If you have any questions about this research, you may contact either:

1) Janice Woods

Email:

Phone:

2) Jane Georges

Email:

Phone:

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant

Date

Name of Participant (**Printed**)

Signature of Investigator

Date

Appendix C: Informational Flyer

Participants needed for a Research Study:

“Perception of Advance Healthcare Planning in Homeless Persons currently living in Long-Term Care”

Must be homeless prior to nursing home admission. Be a nursing home resident

Recorded and confidential interviews about advance healthcare planning with researcher, estimated time about an hour

Free \$25 Visa gift card for participation!

Please call

Janice Woods PhD student for University of San Diego Hahn

School of Nursing,

Appendix D. Interview Script

Hi my name is Janice I am a doctoral nursing student.

I'm here to do an interview on your perception of advance healthcare planning

Can you tell me your age?

Can you tell me what your medical issues are?

Can you tell me your physical function? How do you get around here at the nursing home?

How did you get to be here in the SNF?

What's your religion?

What's your marital status?

Have you seen this pink form?

What can you tell me about this form?

Who explain to you this form?

How does this form make you feel?

Tell more about how you view your health

What do doctors say about your health?

What do you think makes a good death?

What do you think makes a bad death?

How does dialysis make you feel?

When your people talk about "artificial nutrition" what does that mean to you?

What does mechanical ventilation mean? Did you ever experience?

Tell me more about cardiopulmonary resuscitation?

What was your first emergency?

After that event would you make any changes to that?

Have you talked to any family, friends about your health?

Did you choose one and why did you choose that person?

Appendix E: Table of Qualitative Homeless Research Results

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
1	Participant has a sister who made medical decisions for him. Children were not able to help, too busy to help, working. Unaware of medications. Name: supplements, muscle relaxants.	Unaware of hospitalizations - thinks an infection started it. Never went to a doctor prior hospitalization, never took medication prior. Considered healthy after spider bite, which apparently advanced into sepsis. Poor dental hygiene, no teeth. Uninform views of dialysis - view is as a blood pressure strap and put potions in the body- straps to right leg, circulates like a pacemaker and filters blood.	Attempting to go back to work as mechanic. Family left resident there at facility for 8 months. Resident looking for apartment. Resident plans to go to work after 8 months in the SNF in a mechanic shop with his son – enjoys working this his hands (p. 21)	Feels that he can go back to work again. Feels like he can help other residents because he is healthier	Dialysis makes someone crazy. Father was murdered. Advance directive wants sister to be DPOA. Good death = sleep
QUOTES	P. 9 Since I cannot see, she does all my where I'm suppose to sign and all that. P. 10 Well for one she don't have anything to do cause she's retired.	P. 7 They say" I don't know how he doing it, he don't don't where he at. "and so, "poof" I guess doped up I didn't know where I was I didn't that's a scary feeling. And then When you finally wake up out of that you say "damn." Where am I" You need to look around you didn't know what happened. But	P. 11 "I'm trying to get my own place." "I always been (by) myself". P. 18 trying to find a place to go. And they'll have a hard out there right now. It's what I depend everyday my work.	P. 18 "we like the way you'll be pushing us you're gonna be our new what they say our new coach P. 18-19 "don't hang wanna get up and do your therapy. You aint no get to this part. Don't might- that wheelchair hurt your butt I'm trying you. You get out of the wheelchair at least to a walker"	P. 11 "I guess in my sleep." Good death "Pain" bad death "Yeah, I'm really consider that pain.

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
		<p>I knew I was getting sick though” I was started slowing down. But I went to the doctor they gave me appointment, but I never made it to the appointment P. 12</p> <p>Makes you try to pull IV s. I mean the stuff that you might not be there but you could feel it. And that’s what my daughter said I was doing. I kept pulling the IVs out trying to pull the tube out so they can do what they had to do. Strapped my hands down. I And that I didn’t work either. She said I don’t know how you did it. I’m sit over there watching you and your hands just kept moving. Then it went up under the rail like this and come back on the top then went back under. I next thing I know this hand was doing like this P. 21 Yeah I never take no medication <i>so they got a new program where just like the high blood pressure straps they</i></p>		<p>P. 18-19 “I don’t need this walk. I’ll walk walk around the hospital without it” P. 18 “I shake my leg and it’s done there for a minute and go back</p>	

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
		<i>put on on you. The havin' them all over your body. And they hook to a machine and expose your right leg or body parts which are hard. they hook it up to a machine another one somewhere else and it circulates like a pacemaker.</i>			
2	Per resident sister drop him off after his lover pasted away of heart attack and drug overdose, left him homeless, left him out of his will. Participant has had aids since 1985, per resident sister could not take care of him. He is afraid to make his own decisions because he fears his sister will abandon him. advance directive was done Feels entitled, organizations for AIDS should be able to help, P. 10 makes millions of dollars	Drank heavily before, hallucinating did not take medication, sister fears ETOH abuse. Patient denies drinking. After brain injury went to SNF and never got out. Change of doctor of 12 years, new doctor	Feels like he can get his own apartment Cannot get into assisted living because he is too young P. 10	Feels like he can live on his own but his sister prevents him from being independent Feels like he can commit suicide if his health deteriorates. He feels independent because CNAs love to work with him because he does not require much	Decided to be DNR filled out form; had burial cremation. No tube, no dialysis Sister is DPOA Good death: fast no suffering Ok with physician assisted suicide
QUOTES	P. 1 making own decisions “yeah but I don’t want ot piss her off.” “my older sister is the one in charge uh gets my money so right here I pay like 24 hundred.	P. 1- I go to my doctor every 3 months for lab test but my doctor tell me nothing but just to stay here.	P. 2: I just wanna to be free you know but you know my sister doesn’t like me to be free you know. Because I can take my medication and bathe	P. 1 yeah yeah because my doctor said I’m ok to go but my sister doesn’t want me so yeah. Can I tell you? I don’t like this place	P. 6 I just want to go like my mom and dad just go fast. I don’t want to hurt no suffer.

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
	<p>That's all my social secure and pension comes here."</p> <p>"I get \$35...I smoke." P. 6</p> <p>"I'm sacred my sister won't come."</p> <p>P. 8 you know what fucking pisses me off? All these organizations aids like buildings where they go to? They don't have housing for me know that pisses me off you know I can't get housing because I'm 58 I'm suppose to be 60 before they consider me</p>	<p>P. 5 dialysis "flush out and flushing in" through arm,</p>	<p>myself... Well it's hard but I brush my teeth and all that... they just make my bed that's all.... they take me on a shower hair and they bring me to bed and they let me dress myself ... I look for apartments but sister doesn't want it ok because in social secure I get \$2100, I can live on that but my sister.</p> <p>P. 7 ...my sister and I had like a bad credit she talks about that maybe its true because I can set it out about my money and make like 100 dollars with like a house or apartment who care if it's not fully functional like only has a stove that's all I need yea buy things at when I can so.</p> <p>P. 8 and all these and social services tried to help me find places for me but nope no dice. Only 60 and over</p> <p>P. 8 yeah I told her that I have someone for medication I have a nurse</p>	<p>P. 11 no nurses get excited when the nurse aids gets me because they don't do nothing for me. she's happy she got me. Yeah because... [cries] drug overdose and uh...heart attack. So I regret that I didn't tell him to stop, I did tell him to stop but he won't. he won't listen to me he said he would but he didn't and that's fucked up. I'm left without a house and I had to go to my sister and I had him take care of me. i didn't know what to do It was free because fucking my lover broke my contract or will, because he didn't notarize the god mother told me told me to leave. you know all my clothes was there and furniture No I had to come here. I woke up and found myself here. They told me I was only here for physical therapy but bull shit (laughs) bull shit I'm still here</p>	

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
			and I got one to clean and cook that's all I need that's she afraid I might go down where that same path now I don't go through the path	But they have this new form with your medical doctor make that decision for you you can die Yeah, if my sister can't decided than I suicide. If my sister can't make that decision I will tell my doctor...oh but I haven't discussed it with my doctor.	
3	Does not like to live in shelters, noisy loud stressful. On and off homeless for 20 years. Did not want to live out in east la, more familiar with south bay area. Home health nurse convince a podiatrist to write letter to stay in SNF Attempted to get SSI, no success Wants an insurance company to do burial issues	Patient states he is overweight but he is actually obese weigh over 300 lbs. with uncontrolled diabetes and foot wounds and toe amputations 2 years Cascade of health deterioration started after toe amputation, lack of feet wounds d/t diabetes Did not know how surgery would go, unexpected toe amputation. Not going to work lack of income. Hopping from SNF to SNF	Want to live in a cabin up in the mountains or beach. Want a space to call home	Prefer to live in parks away from playgrounds. Does not like to live in shelters causes illness, not convenient because had to leave early in the morning. Pan handle for food such as pizza, hot dogs, burritos and 7-11. Still wants to continue being a man Wants to retire, no longer work	Does not want to be on machines for the rest of life. Wants a trial full code but wants to be unplug P. 9 unreliable family. Friends are mostly alcoholics, looking for and DPOA Good death- no pain, easy death putting to sleep Bad death pain
	P. 12. : just get one of those insurance companies where you pay them and they do it for you. So when you pass away, they you pay money as like they'll cremate you,	So anyways, they call in a procedure and then they brought me the papers to sign for procedures and said we're going to go out there and cut it out. All of	P. 12: I've been watching you know like the last Alaskans and buying in Alaska and seeing that. I like to go to maybe not to Alaska that I could go up	P. 10. I still want to see if I can do it on my own. I mean like I said, don't get me wrong I do appreciate all the help everybody's given me I don't know	P. 8. If I'm on the tubes and everything else, and there's no foreseeable way for me getting any better, except for those tubes and respirators, no unplug me.

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
	<p>you know, in other words, they build you what you want them to do Cremated and spread here</p> <p>Yeah. I use to that place. I knew I was okay there. I mean for the most part. And then my nurse was going to pick me up. I have kind of a nurse that helps me out and she was taking me. I was trying to tell her, I said, look, I said, I know that I'm out here and this ain't better. I need some help. I mean I feel like everybody I've talked to has fall on deaf ears. I said, the longer I stay here on the streets. I know I picked me out here because I didn't want to go to East LA. I said, but there's some where or something, some body, a program, something that you now, because this is me being on the streets, is not beneficial to my health and so that they actually, she's picked me up and took me to my podiatrist, and she talked to</p>	<p>a sudden I'm looking at the [inaudible 15:42]. Here's another paperwork to sign too and then they said, amputation. I go "wait a minute, what's this amputation?" They said "we don't know how bad the infection is, when we get in there, and because don't want to point it out that we'd have to amputate your toe. We'll put you in anesthesia, sign the papers, put you back [inaudible 16:08], and said I have seizures very tricky thing, which I do know about that. So I said, okay and then I go well, am I going to have a [inaudible 16:18] and they said, we don't know. We'll find out when we get in there because we just can't tell how bad the infection is. So I woke up with toe that looks like hamburger, but I did. It was almost healed. Okay</p> <p>I go across the street to 7-11 and I handle them, I</p>	<p>in the mountains and just kick it for a while. Maybe have a cabin. I mean I don't think I could do like how those hard-core guys are doing but I'd like to go up there, you know, go traveling and go in the mountains. Me and my mom always like to go to the mountains quite a bit everywhere San Diego mountain, San Bernardino, the beachies the beaches in the mountain so it doesn't really matter. We camped out on the beach before. I know I kept, well roughly I kind of marking the days but I mean for whatever I do have left, just enjoy and have fun. Try to have fun without bothering anybody. You know just have fun. Yeah Just doing my own thing don't worry about, you know, helping people out in the past, doing this and whatever blah blah blah just like trying to do it for me.</p>	<p>where I'd be without it, But I still want to see if I can do it.</p> <p>Yeah I've had it for a long time you know and all of sudden now I'm in my fifties things kind of go to the short cuts. I'm not really thrilled. I mean I'm not thrilled with my situation. I mean I could of done thing to prevent it. Probably work more than what but what is. So, but I'm here now. So got to make the best what I can do. That makes sense</p>	<p>But if there's a chance I'm going to get better and maybe limited productive life okay. But there's no chance of me living a productive life where I got to be taken care by people, no I mean you know, it depends. In home care or something like that yeah, but I don't want to be ridden. I still want to be able to do somethings on my own</p> <p>P. 11: I would say without pain with pain because I watched my mother and father when they passed away, they were in pain and that stuff. Because that may be kind of questioning god every once in a while. Maybe you got a bit because god is all knowing, all seeing and all caring all loving. Well if he's alling, all know, all carin' all seeing then he knew my mom were dying, but first with the pain, it was prolonged. God knows it. He eventually is going to get my mom and yet he's a</p>

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
	<p>the podiatrist about skilled nursing facility, this place. So He put it in a recommendation and they put in uh they put in a recommendation through my podiatrist and my primary doctor. So I went to another doctor, I forget the name of it. Oh, transitional doctor and he looked at me and evaluated me more closer and while I was sitting in an office. He was already trying to LA care state. This gentleman needs to be off the streets because his feet is that bad beaten...said okay fine. Give me a couple of days to what we can do. I guess about a week later I was here.</p>	<p>buy hot dogs or whatever or burritos or sometimes people would give me food some people would come by and say "what you do you need? You need something to eat?" I'm like "yeah so we'd go and buy me a sandwich then there's a pizza place across the street. They helped me out give me credit. They've been there so long that they kind of knew. "okay well he ain't going anywhere, so okay. I'll give him credit for the pizza and I pay it back in the next couple of days.</p>			<p>loving god, and he is a knowing god, why put them to pain, why not just take them now? What's the sense putting them through pain for longer, when you already know these thing that you already know that my mom and are coming to you. So already know these things that you already know that my mom and dad re coming to you. So why? What I'm saying? I don't question god. I have questions for god.</p>
4	<p>Feels entitled to social security and disabilities Lack of VA benefits Understands that he has to do the "leg work" Being discriminated Learning to utilize government assistive programs</p>	<p>Confuse about how the hospital treated him. Thought it was endocarditis but actually severe urinary tract with urinary retention cystscopy. Chronic back pain and hip pain. Lack of access to care with Medi-Cal insurance</p>	<p>Talking about being divorce and living alone with a dog</p>		<p>Wants full treatment as a trial but if were brain damage will want comfort measures Does not have power of attorney, has friends that were aware Sister is DPOA from ex-wife, no kids, only pets</p>

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
		Lack of getting SSI			
	<p>“...Since SSI and disability paid by my money. Shtye should make it a lot easier. And that a change I know over in the pas like it’s been a change in that the system for people with social security and all other stuff the past 20 years. You know, people have made it sound that you’re you know, “oh you’re a bad person you just gonna the milk the system. You just want free money.” I don’t want free money I paid in to it. I’m sorry it’s not free and I think a lot people are kept ignorant”</p>	<p>That’s was it when I got here I could walk around I’ve been trying to get around even then I’ve taken a little, I’ve had friends coming to take me out and we go out to lunch or whatever. And even then after about 2 hours, 2-3 hours I come back I’m sore I’m tired. Not just like walking to a car to a desk. “oh let’s go over to the food for us so I can get some stuff” And walking in there an d’come out. So just walking and shopping for 30 minutes so you know. I was sore afterward. That enough that I had to take a Norco, which is which is a nother problem, like I don’t like taking narcotics. I don’t like taking pain pills period. I’ll take them if I have to I don’t like taking narcotics</p>	<p>One of my concerns is that when I do get out and I’m trying to find a place to live if there is, is to have her (dog) with me. She’s all that I’ve known how we’re live that all she’s still around you know</p>		<p>Dying, dying, dying quietly in my sleep. You know, would be nice. Yeah, that would be-- you know I would-- I would-- I like-- I would like to death could be a thing where you know you know that would be a nice death. I mean you know heart attack, whatever, it's gonna happen somewhat. Mm, yeah the fear of death is everyone has, but my concern really is not-- 'cause when I'm dead, I'm dead. My mother have the same call, she goes, "When I'm dead, I don't care what you do." But she wanted to be cremated, we cremated her. I told my friends you know, if I die, you know, put me in a boat, Viking-- burn me in a Viking boat off the coast.</p>
5	Relies on staff or store clerks to assist with shopping for groceries mostly buys snacks.	He takes a whole bunch of medications; doesn’t know they name he calls “stomach pills “	Been in 5 nursing homes; does not want to live in nursing homes. Lived one time in and a board and	Feels like independent, the CNAs don’t help much feels disrespected.	No advance directive never got it done. Thinks his sister should make medical decisions

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
	<p>He sees the wound doctor every week blisters occur when he misses appointment</p> <p>Cannot get help outside needs help at the facility</p>	<p>Morbidly obese buys junk food</p> <p>Primary care doctor at SNF does not visit him only relies on the wound doctor, he sees them every week</p> <p>Does not know what a mechanical ventilation is thinks it is a incentive spiraomemter.. Unaware of G-tube feeding thinks it's IV. Precieve his own health has "I'm pretty in good shape all around."</p>	<p>care that was not wheelchair accessible.</p> <p>Keeps changing nursing homes due to his attitude.</p> <p>Aware that he needs to stay in a SNF because no one to help and nowhere to go. Wants to go live in a motel handicap room</p>	<p>When he was homeless, he was independent knew where to find food, had a car</p> <p>Has toys in his room pain them through bank card and SSI, will not pay the nursing home thinks insurance is pay. Wants control of his money and how to spend it</p>	
	<p>They have a bus here that picks up the people that are all on the list to go to Wal-Mart and then you can just go in here you have to push me in my chair 'cuz I don't walk very far without the chair as a result of someone pushes me down the aisles and tell them what I want to buy and then they push me over the counter to check out and they usually after that I'll head over the McDonalds part the store buy some food to eat right there</p>	<p>You know I haven't seen a doctor (at the SNF) at this place for 9 or 10 months ago seems like they don't come in the room and talk to me so I don't know why they are like that</p> <p>Uh I just guess they're stabilizing in otherwise they are not getting real real bad but if I didn't make those appointments blisters would start breaking out of my legs and they would be real bad. That's why I have to maintain those appointments every week</p>	<p>Well the guy of the charge of these homes well, he had 6-7 of these homes in line there in r_____ San B_____ he was trying to find people to live in those homes call board and room type of arrangements. And so I agreed to go but when I got there I found that (chuckles) they didn't even have low thresholds so I couldn't get my chair into the house bricks were all in the front and back and I had to have help lifting me up to get me</p>	<p>I guess I been here now for 9-10 months. And this was no better than before the first time. These homes are not any good because it takes so long to get help when you need help and lot of times they won't even answer their call buttons when your pushing the button to get help or something. So I learned to do everything myself for example I can get up out of this chair I have to grab onto something so I don't fall and I can go over to uh</p>	

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
	<p>This is not a nice place I don't have anybody to help me or have a place to live so I have to stay in this place</p>	<p>Yeah you put a little tube in your moth for about a minute or 2 whatever. Oh I had breathing machines for a while but I'm not on attack. I don't have tank that I carry with me I don't need one where I can breathe fine without using a breathing machine <i>I don't have that problem my kidneys are okay. I would like to find out about all its about and how hard it would be on my body and everything like that before I automatically say I would do it.</i></p>	<p>into the house and when I got into the house they didn't even have a TV that worked I couldn't get out in and out of the bedroom he had for me. When I had my chair somewhere and the bed was on the floor and I have to be able to pull myself up to be able to get out of the bed. So that didn't work out too well. I couldn't even go the bathroom the chair didn't fit through the bathroom. I told him finally he had taken my money which would have been \$600 monthly payment for being able to stay there finally after 3 weeks it was working out and I needed to be sent someplace else so I told him about a motel that would take me , then I found out that the motel didn't want me either so then I was going around to a bunch of motels and finally I landed in the hospital again. From the</p>	<p>bed and get in and out of the bed. I can dress myself. I take my clothes off. I can go to the bathroom by myself without anyone lead me into the bathroom. I can do most everything by myself even then I still don't get any respect and try to make the job easier for them. So they don't have to do a lot work with me. But I still don't get any respect because a lot of times they take 3 to 4 hours come in when I need help I guess the insurance companies are paying for my stay here cause I'm not paying for one penny of it . if they get to the point where they are going to start charging me, I'm going to refuse to do it. because I have toys that are in a facility, I mean a storage and I don't want to lose those.</p>	

Subject	Lack of Self-efficacy	Lack of Awareness of Health	Yearning for a True Home	Locus of Control	Death
			<p>hospital that time they sent me to Arlington gardens which is a pretty nice facility although you can still wait for a long time for service there like you can here and so I eventually left A_____ gardens after 5-6 months then they brought me back here v_____ I guess I been here now for 9-10 months.</p> <p>There was something that I was doing when I was staying at a motel. At a Motel 6 for a while. I was actually paying them weekly rent to have the room and they put me in a handicap room that had a low threshold so I can drive the chair in and out of the room anytime I wanted to. I can get in and out of the bathroom okay. And off and on the toilet and everything then I take care of everything but eh.</p>		
6	Unable to care for himself after his fall	Upset that PCP does not see him at the SNF. Failed hip surgery failed follow up appointment, Surgeon	Looking for an apartment with handicap hopeful here is neighbors	Feels like he is independent able to shower, walk short distances. Use	Does not like dialysis because people don't live that long but his step mother was on short period dialysis

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		failed to know his history and not explain to him why he can't walk Dependent on oxygen View of dialysis		wheelchair, however is wheelchair	Okay with full treatment DPOA is father or uncle Wants physician to determine when to stop treatment. Good death die in your sleep Bad death Burned alive
	... I said I can't even walk I'm not getting released until I can that way you know, if I can at least walk, I can help them clean the house, cook for him and stuff like that. I understood the reasoning He was letting me say there, but hey can't take care of me and living in the back. They can't even go back there you know. No guilt rip in the dark or something, I don't want to risk their lives over me	The doctors here, first time I see you hit one of them. He comes to be a couple of questions and it goes, okay, bye, I'll see you in four months. Remember when I've seen them a couple of times. I've seen the assistant more than I have seen the real doctors. The doctor's assistant now, but before I wouldn't even seen them. I have my own doctor. Oh they wouldn't let me go to mine. At first she was different, run by a different company then, but you said no. They call that double dipping. We got a doctor here and you know your' not allowed to do that. He didn't check what the other doctors. Is it	I'm trying to get on that program thing if I ever get to the bottom of their list or apartment. [Okay. That's your goal, right?] Yeah. That's my goal is to get my own place enough to. I don't need to be here, but those voices I can get help real quick. There's people always watching out for you because you got neighbors that are all your, you know, pretty mature situation. We're all on their last leg. So they watch out for each other. Hmm. Some of them may have a handicap facility to make it easier for you to live in a regular apartment.	Yeah it must be a crazy thing. When you're young, you never think you're going to get old. Do you think about it like that so far? And you just use, put in the trashcan and just keep on enjoy life if you don't prepare for it. We started. Never thought I'd get that old probably	Dying must sleep as my great-grandmother always wished for when had you be over a hundred years old. She died in her sleep. That's how she wanted to go. That was a good way to look at it. Way I'd have the same wish. Granted I would do the same thing ah...Get burned alive or something

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		<p>anything about my case or I'll be put. You know he did the surgery, he didn't ask, You didn't even talk to him. He had no correspondence no medical records set. Nothing like that. He just figured all I can take it around around about a month or two, you asked me, well lawsuit come, you can't walk. He says well I've done everything I can do. He goes I really suggest you know you have to go back to your primary care doctor. Have them give you a x-ray. Maybe you have a broken back.</p> <p>Well, most of the time since I've been sick of using almost continually day and night, normally I try to stay off the daytime, wean myself off because you get to where you feel like you can't live without it. IF you take it off, you feel like you're getting the oxygen feel like you are. It's a crutch that you lean</p>			

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		<p>on it too much. I don't want to get that, so try to keep it just for sleeping at night or when I'm exercising or doing wall all the way down to use the chair here.</p> <p>Yeah I don't know much about it I don't like it. I heard that once you get on it you don't live very long afterwards it's no good.</p> <p>I've know a guy that was on it and he died, my step mother was on t it for a while, but then she got better, so I guess it ain't the end of the world if you start to do it because she got over it somehow</p> <p>Technologies keep always coming up with something new that keeps me alive.</p> <p>As long as they keep all twires, you know what ever.</p>			
7	Unaware what's going	Does not know what health issues	Wants a home	Find place and be able to eat	<p>Good death die in your sleep</p> <p>Bad death shot or stab</p>
		My back and my brain, Unaware of CPR			<p>Go in your sleep I guess</p> <p>Get shot or stab</p>

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8	Don't know where to go Tried Salvation Army, was kicked out for using prescription drugs	Thinks that he has infection of his leg going to get better. Has a depression issue because of his felony.	Moved from the south to get away from troubled pass; was in prison for 6 years. Unemployed in Tennessee. Start new life in California	Looking for work Used God as a way to cope with his depression, felt like he did not need therapy or medication Feels like, because he is a convict, he cannot get a job, reason for his homelessness	Never seen the POLST.
	Yeah yeah you kidding me it's more work than recovery, you work you do classes at night. It is a pretty good program yeah although they kicked me out. I'm half way through it because I took pain medication when I was at the doctors because of my leg because I was in pain and stuff they kicked me out	CPR – it's to pump the chest I don't know to say enough No it's been a year now but you know it was just swelling it wasn't painful in the day when I'm pushing a cart I felt like a twisted a muscle behind my thigh that created the infection so yeah I haven't got a straight answer from the doctor exactly what this is all about that's what I'm looking forward to hearing. The nurse practitioner said I had sepsis you know which is a viral type infection bacterial infection but I'm suppose to see a bacterial infection specialist today yeah so hopefully he shows up	I want things in life, first insurance, a house I want to comfortable live enjoy with laughter with the last years of my life which who knows how long that's going to be here. look over here with my roommate David here is 85 sharp as tack and still getting around well I can die tomorrow who knows but to have things in this world you have to pay for it so I need to go to work it will happened and soon as god says		No no I wouldn't and that when I'm going to have my son buddy going to get a much of heroin so I can just OD and go to sleep and put my family through the agony to watch me deteriorate.

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9	Relying on social services to assist him with SSI, he is blind. He relied on his mother for support but she died.	Does not know why he went blind and cannot walk. Views dialysis as a heart device. Thinks artificial nutrition is a drink..	Wants an apartment, if he can walk better doesn't mind going back to live to a park.	Unable to find work as a truck driver because of his drunk driving.	Good death = die of old age. Bad death when you do not deserve it .
	I'm waiting on my social security and disability come and they are going to place me uh a independent care center place me in that and I can go for there whatever I'm going to be doing I'm going to do it there I lost my job I lost my mother and grand-mother, the people I depended on for support	[Doctor view of health] They didn't tell me nothing [Vision] I can't see it progressed when I was here. Before here I can see good now I can't [CPR] It's when they put you on a heart dialysis and see if your heart is beating and stuff. I don't know what exactly what it means [Artificial nutrition] Artificial nutrition? Is it some kind of drink?	No, I was on the street, I had a sleeping bad, I would have a favorite park that I would go to that I wound have no trouble sleep if I wanted to but I had a sleeping bad, I had equipment that you know accommodated to the weather one for spring and fall. And I have no problem with that it had a roof on top it, a picnic area if it rain I wouldn't get wet. So I was living like that for years (If you didn't break your hip would you still be ok living like that?) Yeah It didn't bother me, I stayed there kept myself clean and in good health	It made me feel good it made me sleep good. I'd go to the library and watch movies with movie player yeah rent movies at the library and watch it in there that was my hobby then When I got laid off all I got was unemployment and insurance for a while and it ran out and I was caught for drunk driving and it wreck my driving record and you know you had to have a good driving record if you want to be a bus driver because some company won't take you and especially drunk driving they won't hire you	Uhhh. I don't know natural causes due to old age that's the way I would see it Young age when you don't deserve it

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10	Cannot find a place to live. Rely on social worker	Thinks he is healthier before he got to the hospital,	Wants to have his own apartment or live with his daughter	Feels like he can get around with his wheelchair and BKA; has a prosthesis	Peaceful death when you don't feel anything a good death is fall asleep and just don't wake up
	Yes, first I would like to go home but they need to find me a place to home to	I feel good right here I have a good um diet	Get out of here. Or maybe with my daughters or something. I really don't know but I would like to be out here		I think it was kind of painful You know what I don't know that to say about that what's a good death, but you know a peaceful death when you don't feel nothing
11	Wants to live in apartment	Aware of psych issues, guarded	Wants to live in apartment		Good death die in sleep, smoke cigarettes Bad death run over
	Waiting for SSI				Like smoke cigarettes before I die and die in my sleep. I don't but if someone got run over
12	Lives in the SNF	Aware that liver is shot but does not know his medication	Wants to live alone		
					Uh, Natural death
13	Lives in nursing home, nowhere to go, no family	Just knows that she was drunk for the reason to be in the SNF. Doctors don't ask her about her health.		Unable to get help due to men (external factor).	
		That I don't know, all I know is that me being homeless uh long period of time I'm that doctors said that when they		Well, they tried (long pause) but I just don't get a long (stutter) with the....um the men. It's...It's more like at the men (long pause) they try	Good way to die Drunk

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		brought me here I was really drunk. uh ... sometimes but they don't really ask me about my health.		to pick up on me...but not only me but the other girls too	